

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Sickle Cell Anemia

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Preface

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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 https://AskJAN.org/soar.

Information about Sickle Cell Anemia

Sickle cell anemia, or sickle cell disease, is a genetically inherited blood disorder that affects the shape of red blood cells. Red blood cells are normally round, smooth, and soft, which allows them to move easily through the blood system. In sickle cell disease, blood cells are crescent, or sickle-shaped, and rigid. This is due to blood cells that contain an abnormal type of hemoglobin. The abnormal shape of red blood cells prevents the cells from properly moving through blood vessels and carrying oxygen to all parts of the body. The sickle-shaped blood cells die sooner than ordinary blood cells, which results in significantly fewer red blood cells and causes anemia.

People with sickle cell disease experience chronic anemia and periodic episodes of pain, sometimes referred to as "crisis." When the sickle-shaped blood cells block the flow of blood and oxygen to the limbs and organs of the body, severe pain and damage to tissues and organs can result. People can experience pain episodes affecting the arms, legs, chest, and abdomen; damage to the lungs, spleen, kidneys, and liver, among other organs; have a stroke; and develop acute chest syndrome and bacterial infections. Symptoms can range from mild to very severe.

Sickle cell disease is a lifelong, chronic condition, and its symptoms can be treated, but for most people there is no cure. People with sickle cell disease often require prophylactic antibiotics, folic acid supplementation, pain management, intravenous fluids, and frequent blood transfusions. Blood transfusions reduce recurrent pain crises, the risk of stroke, and other complications.

Sickle Cell Anemia 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 Sickle Cell Anemia

People with sickle cell anemia 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 who are aging 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

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

Pain

- Industrial
- Adjustable Workstations for Industrial Settings
- Anti-fatigue Matting
- Anti-vibration Gloves
- Anti-vibration Tool Wraps
- Carts
- Compact Material Handling
- Wearable Anti-fatigue Matting
- Office
- Adjustable Workstations for Office Settings
- Alternative Keyboards
- Alternative Mice
- Chairs with Head Support
- Ergonomic and Adjustable Office Chairs
- Ergonomic Assessments
- Ergonomic Equipment
- Forearm Support
- Gooseneck and Other Telephone Holders
- Scribe/Notetaker
- Speech Recognition Software
- Supine Workstations
- Writing Aids
- Other
- Aide/Assistant/Attendant
- Automatic Door Openers
- Flexible Schedule

- Modified Break Schedule
- Scooters
- Service Animal
- Stand-lean Stools
- Telework, Work from Home, Working Remotely
- Worksite Redesign / Modified Workspace
- Workstation Space Heaters

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

Suppressed Immune System

- Disability Awareness/Etiquette Training
- Hand Protection
- Physical/Social Distancing Signage
- Policy Modification
- Telework, Work from Home, Working Remotely
- Worksite Redesign / Modified Workspace

Temperature Sensitivity

- Sensitivity to Cold
 - Air Deflectors
 - Cold Resistant Gloves

- Flexible Schedule
- Heated Clothing
- Heated Ergonomic and Computer Products
- Heated Gloves
- Telework, Work from Home, Working Remotely
- Vent Covers
- Workstation Space Heaters
- Sensitivity to Heat
 - Air Deflectors
 - Cooling Clothing
 - Fans
 - Flexible Schedule
 - Heated Clothing
 - Portable Air Conditioners
 - Telework, Work from Home, Working Remotely
 - Vent Covers

Work-Related Functions

Air Quality/Irritants

- Air Cleaners & Purifiers
- Air Cleaners Chemical/Odor Removal
- Air Cleaning Systems
- Air Purifiers No Ozone
- Air Purifiers for Multiple Chemical Sensitivity
- Alternative Cleaning Supplies
- Carpet Alternatives, Sealants, and Sustainable Flooring
- Escape Hoods
- Flexible Schedule
- Floor Cleaning/Stripping Products Chemical Sensitivity
- Low/No Odor Paints and Stains
- Mask Brackets and Frames

- Masks Respirator
- Masks General/Chemical/Allergen
- Odor Control
- Personal Air Cleaner (Neckworn)
- Powered Air Purifying Respirator (PAPR)
- Telework, Work from Home, Working Remotely

Policies

- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Marginal Functions
- Modified Break Schedule
- Periodic Rest Breaks
- Physical/Social Distancing Signage
- Policy Modification
- Reassignment
- Service Animal
- Sleep Alerting Devices
- Strobe Lights
- Supervisory Methods
- Support Animal
- Telework, Work from Home, Working Remotely
- Touchless Faucets

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

Temperature

- Sensitivity to Cold
 - Air Deflectors
 - Cold Resistant Gloves
 - Flexible Schedule
 - Foot Warmers
 - Heated Clothing
 - Heated Ergonomic and Computer Products
 - Heated Gloves
 - Modified Break Schedule
 - Telework, Work from Home, Working Remotely
 - Vent Covers
 - Workstation Space Heaters
- Sensitivity to Heat
 - Air Deflectors

- Cooling Clothing
- Fans
- Flexible Schedule
- Modified Break Schedule
- Personal Visors
- Telework, Work from Home, Working Remotely
- Vent Covers

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 applicant for a data entry position has sickle cell anemia and discloses that it causes her to have episodes of considerable pain.

The employer agrees to make adjustments to her schedule to allow for flexibility when needed as well as provide some intermittent leave time for more extreme episodes should the individual be hired for the position.

An applicant has compromised immune system function due to their diagnosis of sickle cell anemia.

The applicant is applying to work in a position that requires a great deal of communication with co-workers, which is normally done in person. The employer agrees to provide the individual with protective masks and sanitization products when in-person communication is required, while also allowing the individual to communicate with their co-workers electronically when possible to further reduce exposure if they are hired as an accommodation.

An applicant lets his prospective employer know that he has sickle cell anemia and because of this he experiences blurred vision.

The applicant states that because of this he has trouble reading and the job involves a large amount of reading information on a computer screen. The employer agrees to provide the individual with screen reading software and a headset as an accommodation if he is hired for the position.

An employee with sickle cell anemia has been having problems with typing duties due to his hands swelling.

The employer provides the individual with a speech recognition software and a head controlled input device as accommodations to allow him to use his computer in a manner that does not require him to physically use a keyboard or mouse.

An employee with sickle cell anemia has disclosed that they are experiencing limitations due to chronic fatigue.

The individual has noticed that the quality of her work suffers near the end of their shift and is requesting accommodations to help with this. The employer agrees to modify the individual's schedule so that she has a 1-2 hour break in the middle of the shift as an accommodation so that the individual can rest before resuming the work shift. To accomplish this, the employer extends the individual's shift end-time so the individual works a normal amount of hours despite this long break.

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 Chronic Pain Association

P.O. Box 850 Rocklin, CA 95677-0850 Toll Free: (800) 533-3231

Fax: (916) 632-3208 <u>ACPA@theacpa.org</u> http://www.theacpa.org The purpose of the American Chronic Pain Association is to facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.

American Sickle Cell Anemia Association

10900 Carnegie Avenue DD Bldg. at the Cleveland Clinic, Suite DD1-201 Cleveland, OH 44106

Direct: (216) 229-8600 Fax: (216) 229-4500 <u>irabragg@ascaa.org</u> <u>http://www.ascaa.org</u>

The American Sickle Cell Anemia Association (ASCAA) is an organization that provides quality and comprehensive services through diagnostic testing, evaluation, counseling and supportive services to individuals and families at risk for Sickle Cell Disease.

American Society of Hematology

2021 L Street NW Suite 900 Washington, DC 20036 Direct: (202) 776-0544 Fax: (202) 776-0545

http://www.hematology.org/

The Society's mission is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

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.

Children's Sickle Cell Foundation, Inc.

Gove Business Center 226 Paul St., Suite 105 Pittsburgh, PA 15211 Direct: (412) 488-2723 Fax: (412) 431-5214

support@cscfkids.org https://www.cscfkids.org/

We have continued to impact the lives of children with sickle cell disease (SCD) by providing educational support services including educational advocacy, school work retrieval while the child is absent from school and loaner laptop computers to prevent children from falling behind when their illness interrupts their education.

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.

March of Dimes Foundation

1275 Mamaroneck Avenue White Plains, NY 10605 http://www.marchofdimes.org/

The mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth and infant mortality.

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> <u>https://www.ncbi.nlm.nih.gov/</u>

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

National Heart, Lung, and Blood Institute

P.O. Box 30105 Attention: Website

Bethesda, MD 20824-0105 Direct: (301) 592-8573 Fax: (240) 629-3246 nhlbiinfo@nhlbi.nih.gov/

The National Heart, Lung, and Blood Institute (NHLBI) provides leadership for a national program in diseases of the heart, blood vessels, lung, and blood.

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 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.

Sickle Cell Disease Association of America, Inc.

3700 Koppers Street Suite 570

Baltimore, MD 21227 Toll Free: (800) 421-8453 Direct: (410) 528-1555 Fax: (410) 528-1495

scdaa@sicklecelldisease.org
http://www.sicklecelldisease.org/

The SCDAA's mission is to advocate for and enhance our membership's ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease.

Sickle Cell Information Center

80 Jesse Hill Jr Drive SE PO Box 109 Atlanta, GA 30303 Direct: (404) 616-3572 Fax: (404) 616-5998 aplatt@emory.edu

https://scinfo.org/

The mission of this site is to provide sickle cell patient and professional education, news, research updates and world wide sickle cell resources. It is the mission of our organizations to provide world class compassionate care, education, counseling, and research for patients with sickle cell disease. It is our mission to help break the sickle cycle.

Sickle Cell Society
54 Station Road
London NW10 - 4UA
info@sicklecellsociety.org
http://sicklecellsociety.org/

The Sickle Cell Society believes that individuals with sickle cell disease have the right to quality care. This can only be achieved if funding is made available to educate health carers and other professionals about the condition. The Society aims to provide this. The Society does not discriminate between the types of sickle cell disorders or the ethnic groups concerned. Both sexes are equally affected, and should have equal access to support and services within a confidential and sensitive environment. We respect the views of every patient. We have a network of committed volunteers, who play an important part in running the charity, providing administrative backup, and helping with fund-raising activities.

Wiliam E. Proudford Sick Cell Fund, Inc.

PO Box 979 Dover, DE 19903 Toll Free: (888) 893-6735

Fax: (888) 893-6735 info@wepsicklecell.org/ http://wepsicklecell.org/

Our Mission is to support sickle cell awareness, education, state-of-the-art treatment and research, and to bring hope to families affected by this devastating disease

Wiliam E. Proudford Sick Cell Fund, Inc.

PO Box 42411 Baltimore, MD 21284

Toll Free: (888) 893-6735

Fax: (888) 893-6735 info@wepsicklecell.org http://wepsicklecell.org/

Our Mission is to support sickle cell awareness, education, state-of-the-art treatment and research, and to bring hope to families affected by this devastating disease

World Health Organization

525 Twenty-third Street N.W.

Washington, DC 20037 Direct: (202) 974-3000 Fax: (202) 974-3663

http://www.who.int/en/

We are the directing and coordinating authority on international health within the United Nations' system.

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