

Huntington's Disease Resources

Wisconsin

HDSA Wisconsin Chapter

Social Worker:

Debbie Zwickey, LCSW

dzwickey@hdsa.org

414-257-9499

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Introduction

This HD Resource Guide is intended to provide education and support to the HD families of Wisconsin.

As you use this resource guide, you will notice several references to the Aging and Disability Resource Centers available in each county. Their services are an invaluable resource. Also, the national Huntington Disease Society of America (HDSA) is an excellent source for information on “all things HD”

www.Hdsa.org

Adult Day Services

Adult Day Service is designed for people who want to remain in the community but who cannot be home alone during the day due to a physical, social and/or mental impairment. Adult Day Service also provides respite for family caregivers and especially those who are employed outside the home, and socialization for adults. Services offered in Adult Day Services centers include health monitoring, medication supervision, personal care, and recreational/therapeutic activities. Nutritious lunches and snacks are served, and special diets are provided. Some Adult Day Services may provide their own transportation. Find local Adult Day Services below or call the HDSA Social Worker for assistance.

Name	Contact	Website	Location
Wisconsin Department of Health & Human Services	608-226-1865	www.dhs.wisconsin.gov/guide/adcdir.pdf	Statewide
Aging & Disability Resource Centers (WI Dept of Health Service)	608-226-1865	www.dhs.wiscsconsin.gov/adrc/index	Statewide
Wisconsin Adult Day Services Association	Info@wadsa.org	www.wadsa.org	Statewide

Advance Directives

Advance Directives are documents that let you put your health care wishes on paper so that medical providers, family members, and others will know what you want. In most cases, it avoids the need for guardianship, an expensive and difficult process. Most importantly, it is meant to ensure that you choose what you want for your care, who will speak for you, and where you will receive your care. Then you must write down your wishes and sign the documents to make it official.

Name	Contact	Website	Location
Wisconsin Department of Health Services	608-226-1865	www.dhs.wisconsin.gov/forms/advdirectives/index.htm	Statewide
EverPlans	Online	www.everplans.com	Nationwide
Five Wishes	850-681-2010	www.agingwithdignity.org	Nationwide

Aging & Disability Resources Centers (ADRC)

The Aging & Disability Resources Center (ADRC) offices provide information about resources and support on all aspects of life related to aging or living with a disability.

The ADRC is also the access point for information about long-term care options and applying for public benefits. Services are free and available to all Wisconsin residents.

Name	Contact	Website	Location
Aging & Disability Resource Center	Online	www.dhs.wisconsin.gov/adrc/consumer/index.htm	Countywide
Wisconsin Department of Health Services	608-226-1865	www.dhs.wisconsin.gov/adrc	Statewide

Assistive Devices/Aids for Daily Living

Assistive devices help with daily activities and encourage independent living. Your doctor can make recommendations or refer you to an Occupational Therapist.

Name	Contact	Website	Location
Wisconsin's Assistive Technology Program	608-266-1865	https://www.dhs.wisconsin.gov/disabilities/wistech/index.htm	Statewide
Senior Living	Online	www.seniorliving.org/products/atds	Nationwide

Body and Brain Donation

If you are contemplating body or brain donation, please reach out to the following agencies to begin the consent and registration process. You can change your mind at any time, even after registering.

Donations are much more difficult to process after someone has died, so it is crucial to plan ahead of time.

Name	Contact	Website	Location
Medical College of Wisconsin	414-955-8261	www.mcw.edu/department/s/cell-biology-neurobiology-and-anatomy/body-donation	Statewide
University of Wisconsin-Madison School of Medicine	608-262-2888	www.bdp.wisc.edu	Statewide
Harvard Medical Brain Tissue Resource Center	800-272-4622 McLean Hospital 115 Mill Street Belmont, MA	www.hbtrc.mclean.harvard.edu	Nationwide
Brain Support Network	Online	www.brainsupportnetwork.org	Nationwide

Books on HD

Below are some books about HD and coping with illness. HDSA does not endorse or recommend any, but simply would like to offer options for those interested in reading books on HD

Book Title	Author
Ambiguous Loss: Learning How to Live with Unresolved Grief	Pauline Boss
Mapping Fate: A Memoir of Family, Risk, and Genetic Research	Alice Wexler
The Woman Who Walked Into the Sea: Huntington's and the Making of a Genetic Disease	Alice Wexler
Faces of Huntington's	Carmen Leal
Walking the Tightrope: Living at Risk for HD	Randi Jones
Hurry Up and Wait! A Cognitive Care Companion (Huntington's Disease in the Middle and More Advanced Years)	Jimmy Pollard
Learning to Live with Huntington's Disease: One Family's Story	Sandy Sulaiman
Gene Hunter: The Story of Neuropsychologist Nancy Wexler	Adele Glimm
HDSA Publication List	www.hdsa.org
The Anatomy of Hope	Jerome Groopman
After Diagnosis	Julian Seifter
When Given Lemons	Lauren Holder
It's Better to Laugh than to Cry	Clarence Vos
Homeward Journey	Leslie Foor
Inside the O'Briens	Lisa Genova
Someone Else's Life	Katie Dale
Devil's Dance	Richard Karlen
Could I Have This Dance	Harry Kraus, MD

Budgeting

Finding a workable budget can be extremely frustrating. The following agency offers personal counseling on a variety of financial matters: credit card debt, bankruptcy, budgeting and more.

Name	Contact	Website	Location
Financial Information & Services Center (FISC)	800-366-8161	www.fisc-cccs.org	Statewide

Caregiver Information and Support

Caregiving is often a full-time job, thus necessitating the need for support for both the individual with HD, as well as, the caregiver.

Name	Contact	Website	Location
Aging & Disability Resource Centers	608-226-1865	www.dhs.wisconsin.gov/adc/index	Statewide
Wisconsin Family Caregiver Support Program	866-843-9810	www.wisconsin caregiver.org	Statewide
Wisconsin Chapter-HDSA	414-257-9499	www.dzwickey@hdsa.org Contact WI HDSA Social Worker for more information on counseling, referrals, and HD Support Groups. Support groups are now available in: Eau Claire, Madison, Milwaukee, Oshkosh, and Wausau	Statewide
HD Online Caregiver Support Group	Online	www.hdsa.org/osg	Nationwide

Reading Materials:

Book Title	Author
Hurry Up and Wait!	Jimmy Pollard
HDSA Caregiver Guide. Found at www.hdsa.org or contact WI Chapter Social Worker to request a copy.	HDSA

Counseling

Counseling/therapy can be extremely beneficial in helping to cope with the stresses associated with HD. It can also help develop healthy coping skills.

Contact your Physician or the Chapter Social Worker for referrals to a therapist in your area. Also, contact your insurance company/provider for their list of covered (in network) providers. In a mental health emergency, call 911 or go to the nearest hospital emergency room.

The National Alliance of the Mentally Ill (NAMI) is an excellent resource in your community offering education, support, and advocacy.

HDSA Telehealth is a free internet-based program that provides up to eight telehealth visits per year/per family member with qualified licensed Social Workers and Psychologists.

Name	Contact	Website	Location
National Alliance of the Mentally Ill (NAMI)	Online	www.namiwisconsin.org	Statewide
HDSA Telehealth	Online	www.hdsa.amwell.com www.hdsa.org/telehealth	Nationwide

Dental Care

Dental care can be difficult for individuals with HD due to movements, clenching, and swallowing difficulties. There are, however, several options including sedation dentistry, prescription toothpastes, “paint brushing” with mouthwash, etc.

Name	Contact	Website	Location
Marquette University School of Dentistry	414-288-6790		Statewide
Tri-County Dental	9200-882-5500	www.tricountydental.org	Statewide
Wisconsin guide to free or low-cost dental care	Online	www.dhs.wisconsin.gov/guide/freedental/html	Statewide
Special Care Dentistry Association (SDCA)	Online	www.scdonline.org/default.aspx	Nationwide
Specialized Care Co. Dental Products	Online	www.specializedcare.com	Nationwide

Energy Assistance

Wisconsin Division of Energy Assistance oversees the providing of financial assistance to help eligible households pay a portion of their heating and electric energy costs.

Name	Contact	Website	Location
Wisconsin Home Energy Assistance Program (WHEAP)	866-432-8947	www.homeenergyplus.wi.gov	Statewide
Wisconsin Public Service	Online	www.wisconsinpublicservice.com/homeenergyassistance	Statewide
Wisconsin Weatherized Assistance Program (WISWAP)	Online	www.homeenergyplus.wi.gov	Statewide

Family Planning

The decision to have children within an HD family can be a difficult decision to navigate as there are many decisions and choices to make. The resources below are available to help in this planning process in order to make the most informed and appropriate choice for you and your family. Please call the Social Worker for additional resources and referrals.

Name	Contact	Website	Location
Having a Family, The HD Way (from HD Buzz)	Online	http://en.hdbuzz.net/036	Nationwide
Help Cure HD (Provides grants for PGD-IVF)	Online	http://helpcurehd.org/application.2-3/	Nationwide
HD Free with PGD	Online	www.hdfreewithpgd.com/	Nationwide
Reproductive Genetics Institute	773-472-4900	www.reproductivegenetics.com/	Nationwide

Federal Lifeline Programs (Wireless/Phone Assistance)

There are programs that provide free or reduced pricing on cell phones and calling plans to individuals who qualify. If you receive other benefits, such as SSD, SSI, Badger Care, or Food Share, you may be eligible.

Name	Contact	Website	Location
Lifeline	Online	www.lifelinesupport.org	Nationwide
Safelink Wireless	800-723-3546	www.safelinkwireless.com	Nationwide

Food and Nutrition Assistance

These are programs that can help you pay for healthy food.

Name	Contact	Website	Location
Food Pantries in Wisconsin	Online	www.foodpantries.org/st/wisconsin	Statewide
Wisconsin Community Action Program Association	Online	www.wiscap.org	Statewide
Wisconsin Department of Health Services	608-266-1865	www.dhs.wisconsin.gov/prevention-healthy-living/nutrition-food-assistance.htm	Statewide
Emergency Food Assistance Program (TEFAP)	608-267-9071	www.hds.wisconsin.gov/nutrition/tefap/index.htm	Nationwide
Feeding America- Locate your local food bank	800-771-2303	www.feedingamerica.org/foodbank-results.aspx	Nationwide

Funeral Planning

Pre-planning a funeral for a relative, friend, or one's self can be difficult, but it makes good sense. People often have different reasons for making these plans, such as financial factors, wanting to lease the burden on their loved ones, etc. It is important that you have as much information about options before making any final decisions.

Name	Contact	Website	Location
Wisconsin Consumer Guide (to pre-plan a funeral)	Online	https://dps.wi.gov/Credentiaing/business/fm2357.pdf	Statewide
My Way Forward	Online	www.mywayforward.com/	Nationwide
National Funeral Directors Association	Online	www.nfda.org/planning-a-funeral.com	Nationwide

Genetic Counseling/Testing

The decision to test or not to test for Huntington's Disease is a very difficult choice and very personal to each individual. Many people see no benefit in knowing that they will someday develop the disease. Others want an end to uncertainty so that they can make informed choices about the future. Please call the Chapter Social Worker should you want to discuss further or want to process this difficult decision.

Name	Contact	Website/Address	Location
Wisconsin Genetic Counseling Center	Online	www.wigca.org To find a center close to you, click on "Public", then "Find a Genetic Counselor", then enter your zip code and state, and specify "neurogenetics" on the drop down screen labeled "Types of Specialization"	Statewide
Wisconsin HDSA Center of Excellence- Madison	608-263-5442	4602 Eastpark Blvd. Madison, WI 53718	Statewide

Genetic Discrimination

Know your rights regarding Genetic Information Non-Discrimination Act (GINA), which created protections against the misuse of people's genetic information by health insurance and employers. Please consult a genetic counselor and/or Social Worker before and after testing.

Name	Contact	Website	Location
Genetic Non-Discrimination Act	Online	www.genome.gov	Nationwide
HDSA	Online	www.hdsa.org/living-with-hd.gina	Nationwide

Grief and Loss

Losing someone you love can be a very painful process, with multiple emotions coming to the surface. There are no right or wrong ways to deal with grief but seeking the support of others can be beneficial for you. Below are some grief and loss resources to explore. Also, your physician, church, or local funeral home may be able to provide a referral to either a grief therapist or grief support group. In addition, you may call the WI HDSA Social Worker for help.

Name	Contact	Website	Location
Horizon Grief Resource Center	414-586-8383	www.horizonhomecareandhospice.org/grief-resources/grief-resource-center/	Statewide
Grief Share Support Groups	Online	www.griefshare.org (to find a group near you, search by zip code)	Nationwide

Guardianship

Guardianship is a court order granting someone the legal authority to oversee another person's affairs when that person is deemed incapable of managing their own affairs. Guardianship can be a very difficult process- both emotionally and logistically. Below are resources to help through the process

Name	Contact	Website	Location
Aging & Disability Resource Center	608-226-1865	www.hds.wisconsin.gov/adc/index	Statewide
Wisconsin Guardianship Association	Online	www.wisconsin-guardianship-association.com	Statewide
National Academy of Elder Law Attorneys	Online	www.naela.org	Nationwide

HD Medical Care in Wisconsin

The clinics listed below offer health and medical support for individuals with HD. Please call the clinic directly to obtain information or schedule an appointment. Also, please contact your health insurance to inquire if the clinics below are covered under your plan.

Name	Contact	Website	Location
HD Center of Excellence UW Health American Center 4602 Eastpark Blvd Madison, WI 53718	608-263-5442 Specialists in HD & Movement Disorders: Dr. Laura Shannon Dr. Laura J. Buyan-Dent Dr. Jessica Baker Dr. Catherine L. Gallagher Dr. Teresa Mangin Adrienne C. Gasper, NP	www.uwhealth.org/neurology/movementdisorders	Madison
Froedtert Hospital & Medical Clinics 9200 W. Wisconsin Ave Milwaukee, WI 53226	414-805-8710 Dr. Karen Blindauer Dr. Ryan Brennan Dr. Sheila Eichenseer	www.froedtert.com/parkinsons-movement	Milwaukee
Marshfield Clinic Wausau Center 2727 Plaza Dr Wausau, WI 54401	715-847-3339 Dr. Katie Spangler	www.marshfieldclinic.org	Wausau
Mayo Clinic 1221 Whipple St Eau Claire, WI 54703	715-838-1900 Dr. Leonardo Fugoso	www.mayoclinichealthsystem.org	Eau Claire

HD Research Information & Clinical Trials

Explore the following resources if you are interested in learning about or participating in a current clinical trial.

Name	Website
Enroll HD	www.enroll-hd.org/
HD Trial Finder	www.hdtrialfinder.org
Huntington Study Group	www.huntingtonstudygroup.org
HD Buzz	www.hdbuzz.net
CHDI Foundation	www.chdifoundation.org
U.S. National Library of Medicine	www.clinicaltrials.gov

HD Specific Resources

These resources are dedicated to outreach, education, and advocacy for those affected by HD.

Name	Contact	Website	Location
Huntington's Disease Society of America (HDSA)	800-345-4372 505 Eighth Ave Suite 902 New York, NY 10018	www.hdsa.org	Nationwide
Huntington's Disease National Youth Alliance (NYA)	Online	www.nya.hdsa.org	Nationwide
HD Lighthouse Family Caregiver Alliance	Online	www.caregiver.org/hd-lighthouse	Nationwide
HD Buzz	Online	www.hdbuzz.net/	Nationwide

Home Health and In-Home Assistance

Home Health care services provide a range of medical services in a home setting such as physical therapy, speech therapy, occupational therapy, medical assistance, nursing services, etc. A therapist can also be ordered to come to your home for a home safety/modification evaluation. Home health, which needs a physician's order, is short term and is covered by most health insurances. Please contact your insurance to locate home health agencies in your area. Please contact your doctor to request an order for home health.

In-home care services involve help with activities of daily living (example: dressing, bathing, grooming), companionship, light housekeeping, grocery shopping and more. These services are usually NOT covered by health insurance and the hourly rates will vary by agency. Check with the HDSA Social Worker for resources to assist with payment.

Name	Contact	Website	Location
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adc/index	Statewide
Wisconsin Consumer Guide to Health Care for Home Health offers county by county directories of Wisconsin home health agencies, background checks and more.	Online	www.dhs.wisconsin.gov/regulations/hha/introduction.htm	Statewide

Home Modifications/Accessibility

People with disabilities who plan to stay in the home often need accommodations in the home to ensure that the environment is safe. Below are some agencies who provide these home modifications, as well as, some links to potential funding sources to help with the costs.

Name	Contact	Website	Location
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adc/index	Statewide
Wisconsin Builders Association	Online	www.wisbuild.org	Statewide
Wisconsin Department of Health Services	608-266-1865	www.dhs.wisconsin.gov/disabilities/physical/housing-resources.htm	Statewide
Express Ramps	866-491-1110	www.adawheelchairramps.com	Nationwide
Ramps.org	Online	www.ramps.org	Nationwide

Hospice and Palliative Care

Hospice and Palliative care offer services and therapies to individuals who are in the later stages of HD and help the individual and family to improve quality of life as best as possible. The team consists of nurses, social workers, chaplains, and volunteers. Palliative care is offered through medical clinics and is associated with hospice. Hospice is covered by most health insurances; however, it does not provide 24-hour direct caregiving to individuals. Please contact your physician for a referral.

Name	Contact	Website	Location
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adc/index	Statewide
Wisconsin Department of Health Services	608-266-1865	www.dhs.wisconsin.gov/guide-hospice This link will also give you access to the statewide hospice directory and the Consumer Guide to Health Care for Hospice	Statewide
National Hospice and Palliative Care Organization	Online	www.nhpco.org	Nationwide

Housing: Residential Care and Assisted Living

When it becomes necessary, your loved one may need care beyond which you can provide at home. This may include either assisted living or a long-term care facility. The following resources can help you navigate this process. Please call the HDSA Social Worker for assistance in finding a facility familiar with Huntington's Disease.

Name	Contact	Website	Location
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adrc/index	Statewide
Wisconsin Department of Health Services	Online	www.dhs.wisconsin.gov/regulations/nh/introcution.com www.dhs.wisconsin.gov/assisted-living/resources.com These sites give you the link to "The WI Consumer Guide to Health Care: Finding and Choosing a Nursing Home". This guide provides helpful information to help you find a facility, review state surveys and citation information, etc.	Statewide
Centers for Medicare and Medicaid Services (CMS)- Nursing home comparison website	Online	https://www.medicare.gov/nursinghomecompare/search.html	Nationwide

Incontinence Resources

The cost of adult incontinence supplies can often be expensive. Below are some resources that may help with the cost of supplies

Name	Contact	Website	Location
Wisconsin Department of Health Services	608-266-1865	www.dhs.wisconsin.gov/lookup-incontinence	Statewide
J & B Medical	800-737-0045	www.jandbmedical.com/wisconsin-medicare-diaper-and-incontinence-supplies-program/	Statewide
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adrc/index	Countywide

Insurance

Resources below may help with obtaining application information to apply for various insurance benefits. These include medical insurance, life insurance, and long-term care insurance. If exploring medical plans under the Health Care Reform Act, the state HDSA Social Worker strongly recommends meeting face-to-face with an ADRC representative to discuss options.

MEDICAL INSURANCE:

Name	Contact	Website	Location
Badger Care/Medicaid (State of Wisconsin)	Online	www.healthinsurance.org/wisconsin-state-health-insurance-exchange/	Statewide
Social Security Insurance (SSI)	Online	www.dhs.wisconsin.gov/medicaid/ssi-related.htm	Statewide
Medicare	Online	www.medicare.gov	Nationwide
Health Care Reform Act	Online	www.healthcare.gov	Nationwide
Health Care Solutions (private insurance options)	Online	www.lebinsurancegroup.com	Nationwide

LIFE INSURANCE:

Name	Contact	Website	Location
National Association of Insurance and Financial Advisors in Wisconsin	Online	www.naifawisconsin.org	Statewide

ADDITIONAL RELATED RESOURCES:

Name	Contact	Website	Location
Family Medical Leave Act	Online	www.dol.gov/whd/fmla	Nationwide
Healthwell Foundation	Online	www.hdsa.org/news/healthwell-foundation-opens-huntingtons-disease-fund-to-assist-medicare-patients/ (HDSA maintains a partnership with an independent non-profit, that provides a financial lifeline for inadequately insured Americans suffering from a movement disorder)	Nationwide
HDSA- Genetic Information Non-discrimination Act	Online	www.hdsa/gina	Nationwide

Legal Assistance

Legal assistance can include advocacy, estate/special needs planning, elder/disability law, criminal, housing, health and government benefits. Also, see Advance Directives section of this resource guide. Please contact HDSA Social Worker for referrals in your local area or contact your personal attorney.

Name	Contact	Website	Location
Wisconsin Aging and Disability Resource Center (ADRC)	608-266-1865	www.dhs.wisconsin.gov/adc/index	Statewide
Wisconsin Legal Assistance Hotline	800-362-9082	www.wilalibrary.gov/topics/assist.php (If you are looking for general legal information or an answer to a simple legal question, the State Bar's lawyer and information service will make an appointment for you to speak with an attorney free of charge.)	Statewide
Elder Law Answers	Online	www.elderlawanswers.com	Statewide
Legal Advice	Online	www.legalaction.org	Nationwide
Free Legal Answers	Online	www.freelegalanswers.org	Nationwide

Medical Alert Systems

Medical alert systems are a great tool for maintaining both independence and safety in your home, as they connect people with disabilities to those who can help them in the event of a fall or other emergency. When a person falls, they can press the button for assistance. Some systems even detect a fall without the person needing to push the button as this might be impossible for them in that moment. The device will call your identified emergency contacts, as well, as 9-1-1, depending on the agreed upon protocol when you purchase a system. Please see below to find a system that is right for you and your loved one.

Name	Contact	Website	Location
In Home Safety Guide	Online	www.inhomesafetyguide.org	Nationwide
Consumer Affairs	Online	www.consumeraffairs.com/medical-alert-systems/#	Nationwide

Medical/Safety Equipment

Always consult your medical team for recommendations on safety and appropriateness of medical equipment. Some equipment may be available through your health insurance and prescription from your doctor. Equipment not covered can always be purchased privately and costs will vary. Equipment may also be available at consignment stores, local churches, etc. Make sure you inspect all equipment before purchasing or using to ensure safety.

Name	Contact	Website	Location
Wisconsin Department of Health	608-266-1865	www.dhs.wisconsin.gov/disabilities/wistech/dme.htm	Statewide
Katy's Kloset (Non-profit organization that lends medical equipment free of charge)	Online	www.teamupwithfamilies.org	Statewide
Broda Seating	800-668-0637	www.seatingisbelieving.com	Nationwide
Care Form Chairs	877-236-2687	www.carefoam.com	Nationwide
The Safety Sleeper	Online	www.thesafetysleeper.com	Nationwide
Stanford University	Online	https://hopes.stanford.edu/mobility-devices-for-huntingtons-disease	Nationwide
Vita Care	Online	www.vitacaremedical.com	Nationwide
Huntington's Disease ID Bracelet	Online	www.hdsa.org/product/hd-id-bracelet-2	Nationwide

Medicare Observation Status

When a Medicare beneficiary is hospitalized for any reason, it is important to ask the hospital whether they are admitted as an inpatient or on observation status, as this can mean a big difference in coverage and discharge plans. See resources and more information below.

Name	Contact	Website	Location
Medicare Self Help Kit	Online	www.medicareadvocacy.org/ self-help-packet-for- medicare-observation-status/	Nationwide
Society of Hospital Medicine	Online	https://www.hospitalmedicin e.org/policy-- advocacy/current- issue/observation-status/	Nationwide

Medication Assistance

The following resources may offer medication payment assistance, discounted medications and/or free clinics. Certain medications may be obtained free from the manufacturer with a prescription from your doctor accompanied by an application which verifies your income if they offer a Patient Assistance Program.

Name	Contact	Website	Location
Wisconsin Department of Health Services	608-266-1865	https://www.dhs.wisconsin.gov/guide/freeprescr.htm	Statewide
Wisconsin Drug Card	Online	www.wisconsindrugcard.com	Statewide
Health Well Foundation	800-675-8416	www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/	Nationwide
National Organization for Rare Disorders	Online	www.rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs-2/	Nationwide
Xenazine	888-882-6013	www.xenazineusa.com	Nationwide
Austedo/Shared Solutions	800-877-8100	www.austedo.com or www.sharesolutions.com	Nationwide
Bio Tek (Remedy's Foundation)	877-246-9104	www.biotekrx.com/specialties	Nationwide

Nutrition & Food

People with HD often need more calories than most people. As a result, they may need assistance with recipes, home delivered meals, etc. Your physician may also refer you to a registered dietician.

Name	Contact	Website	Location
Meals on Wheels	Contact your local ADRC	www.adrc-cw.org/meals-for-seniors/meals-on-wheels	Local
Wisconsin Department of Health Services	608-266-1865	www.dhs.wisconsin.gov/aging/nutrition.htm	Statewide
HDSA	Online	www.hdsa.org/nutrition	National
Swallowing Disorder Foundation	Online	www.swallowingdisorderfoundation.com	Nationwide
<u>Cookbooks:</u> Easy to Swallow, Easy to Chew (Paula Sullivan) The I Can't Chew Cookbook (J. Randy Wilson) Soft Foods for Easier Eating Cookbook (Sandra Woodruff)			

Occupational Therapy

Occupational therapy can be very beneficial to help those with HD maximize independence and safety with daily activities. Occupational therapists can provide home safety assessments as well. In addition, they are an excellent resource for assistive devices to help with fine motor skills, safety, balance, endurance and overall functioning. Ask your physician for a referral.

Name	Contact	Website	Location
HDSA Occupational Therapy Guide	Online	http://hdsa.org/product/hdsa-family-guide-series-physical-and-occupational-therapy-huntingtons-disease/	Nationwide

Optical Care

There are several resources that offer comprehensive eye care services for low-income families who do not have vision/eye care insurance

Name	Contact	Website	Location
State of Wisconsin Free Vision Guide	Online	www.dhs.wisconsin.gov/guide/freevision.htm	Statewide
Vision USA- The Wisconsin Project	877-435-2020	www.woa-eyes.org/vision-usa-public .	Statewide
Sight for Students	888-290-4964	n/a	Nationwide
Eyecare America (a public service program of the American Academy of Ophthalmology)	Online	www.aao.org/eyecare-america	Nationwide

Pet Therapy

Research has shown that owning a pet can be beneficial in helping reduce pain, blood pressure, anxiety, and depression in people with a range of health problems. They can also bring much joy into our lives. However, sometimes caring for a pet can be stressful and costly. Carefully weigh the pros and cons before adopting a pet. Contact your local Humane Society or rescue groups to explore your options.

Physical Therapy

Physical Therapy can be very helpful in improving the overall quality of life. Addressing the benefits of exercise, range of motion issues, and balance concerns; a physical therapist can be an invaluable resource. Your physician can refer you to an experienced therapist.

Name	Contact	Website	Location
HDSA (HDSA offers several online resources concerning the importance of physical therapy, including the HDSA Physical Therapy Guide, Gait & Balance from HDSA, and Early Intervention with PT from the Marker.	Online	www.hdsa.org/shop/publications/physical-occupational-therapy/	Nationwide

Research Information

Many biotechnology companies are actively working on treatments for HD. To learn more, see below:

Name	Contact	Website	Location
Genentech (a member of the Roche group)	online	www.gene.com	Nationwide
Ionis	online	www.ionispharma.com	Nationwide
PTC Therapeutics	online	www.ptcbio.org	Nationwide
Sage Therapeutics	online	www.sagerx.com	Nationwide
UniQure	online	www.unique.com	Nationwide
Vaccinex, Inc	online	www.vaccinex.com	Nationwide
Voyager Therapeutics	online	www.voyagertherapeutics.com	Nationwide
Wave Life Sciences	online	www.wavelifesciences.com	Nationwide

Respite

Respite care is a planned or emergency care provided to an individual with special needs in order to provide temporary relief to family caregivers. Respite programs are available through private home health agencies. Assisted living facilities also offer respite services for a daily or weekly fee. These are typically not covered by insurance. Please contact your HDSA Social Worker or Physician for a referral.

Name	Contact	Website	Location
Arch Respite Locator	Online	www.archrespite.org	Local
Aging & Disability Resource Center (ADRC)	Online	www.dhs.wisconsin.gov/adrc/consumer/index.htm	Countywide
Respite Care	608-222-2033	www.respitecarewi.org	Statewide

Social Security/Financial Benefits

The Social Security and Supplemental Security Income Disability programs are the largest of several federal programs that provide assistance to people with disabilities. Both programs are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify. Contact your local Social Security office for more information or help with the application process.

Name	Contact	Website	Location
Aging & Disability Resource Centers (ADRC)	608-226-1865	www.dhs.wisconsin.gov/adrc/index	Statewide
Benefits Checkup	Online	www.benefitscheckup.org	Nationwide
Social Security Disability	800-772-1213	www.ssa.gov	Nationwide
SSDI Tips	Online	www.hdsa.org/living-with-huntingtons/family-care/disability.html	Nationwide
HDSA Disability Toolkit	Online	www.hdsa.org/disability	Nationwide
HDSA Disability Program Manager (Allison Bartlett)	212-242-1968 ext. 218	abartlett@hdsa.org	Nationwide

Speech Therapy

Speech and swallowing difficulties are common in HD patients. A speech therapist can be extremely helpful with these changes and can work with the individual to improve quality of life. Ask your physician for a referral.

Name	Contact	Website	Location
American Speech-Language-Hearing Association	Online	www.asha.org/findpro/	Nationwide
Coping with Speech and Swallowing Difficulties	Online	www.hdsa.org/images/content/1/1/11684.pdf	Nationwide
Communication and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/communications-and-hd/	International
Swallowing and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/swallowing-and-hd/	International

Support Groups in Wisconsin

Support groups are beneficial to help you meet and connect with other individuals who are going through similar life changes and obstacles. Please contact the HDSA Wisconsin Chapter Social Worker for more information.

Name	Location	Meeting day/time	Contact
Eau Claire	Trinity Lutheran Church 1314 Lexington Blvd. Eau Claire	1 st Saturday of the month (10am-11:30am)	Debbie Gilbertson (debbie.gilbertson1@gmail.com)
Madison	UW Health American Center 4602 Eastpark Blvd. (Room # 1920) Madison	Contact Debbie Zwickey for dates (10:30am- noon)	Debbie Zwickey (dzwickey@hdsa.org) 414-257-9949
Milwaukee	Froedtert Hospital Community Conference Center 8700 Watertown Plank Rd (Room #2) Milwaukee	3 rd Saturday of the month (10:30am-noon)	Amy Merkel (starfishyoga@yahoo.com) 262-330-4075
Oshkosh	Oshkosh Fire Station #17 1813 Algoma Blvd. Community Room Oshkosh	Contact Debbie Zwickey for dates (10:30am-noon)	Debbie Zwickey (dzwickey@hdsa.org) 414-257-9949
Wausau	Marathon County Public Library 300 1 st St Wausau	1 st Saturday of the month (10am-11:30am)	Behavioral Health Clinic of Wausau 715-842-9500

Transportation- Assistance with Obtaining a Wheelchair Accessible Van/Adaptive Driving

Wisconsin agencies, some of which are non-profit, and others are government run, provide transportation assistance to individuals living with a disability. Your county's ADRC office may also help with reduced costs of public transportation.

Name	Contact	Website	Location
Aging and Disability Center (ADRC)	Online	www.dhs.wisconsin.gov/adr_c	Statewide
Division of Vocational Rehabilitation	800-422-3477	https://dwd.wisconsin.gov/dvr	Statewide
Governor's Committee for People with Disabilities (GCPD)	608-261-7816	https://gcpd.wisconsin.gov/	Statewide
Wisconsin's Assistive Technology Program (WisTech)	Online	www.dhs.wisconsin.gov/disabilities/wistech/index.htm	Statewide
Access Unlimited (making your vehicle accessible)	800-849-2143	www.accessunlimited.com/	Statewide

Transportation- Driver's License Evaluation and Safety

Individuals with HD may at some point lose their ability to drive. A formal driving evaluation, at an occupational therapy or rehabilitation center, can help both the physician and the person with HD by providing objective information about the individual's performance.

Name	Contact	Website	Location
Wisconsin Department of Transportation	Online	https://wisconsindot.gov	Statewide
Center for Mature Market Excellence (family conversations with older drivers)	Online	www.thehartford.com www.hartfordauto.thehartford.com/	Nationwide
AARP	Online	www.aarp.org/autodriversafety	Nationwide
Keeping Us Safe: Driving Agreements & Contracts	877-907-8841	www.keepingussafe.org	Nationwide

Traveling with HD

Sometimes traveling, while enduring symptoms of HD, can be difficult. Please see the below resources for assistance with travel. Travel agents are also a valuable source of information.

Name	Contact	Website	Location
TSA Care	855-787-2227	https://www.tsa.gov/travel/passenger-support	Nationwide
Rick Steves Travel Tips	Online	www.ricksteves.com/travel-tips/trip-planning/travelers-with-disabilities	Nationwide
Society for Accessible Travel and Hospitality	212-447-7284	www.sath.org/	Nationwide
Travel Channel: 10 Tips for Traveling with a Physical Disability	Online	www.travelchannel.com/traveling-with-physical-disabilities	Nationwide
Huntington Disease Society of Canada	Online	www.huntingtonsociety.ca/travellingwithhuntingtondisease	International

Virtual Caregiving Devices

Virtual caregiving devices can help provide you peace of mind, while enhancing independence, as much as possible, in the home.

Name	Contact	Website	Location
9 Need-to-know Tech must haves for Caregivers	Online	http://blog.aarp.org/2012/04/26/sally-abrahms-caregiving-technology-must-haves/	Nationwide
Digital Technology for the Family Caregiver (Family Caregiver Alliance)	Online	http://caregiver.org/digital-technology-family-caregiver	Nationwide
Alarm.com Wellness	Online	www.alarm.com	Nationwide

Vocational Assistance

The Wisconsin Division of Vocational Rehabilitation is a federal/state program designed to assist individuals with disabilities in obtaining, maintaining, or improving employment.

Name	Contact	Website	Location
Wisconsin Department of Workforce Development	608-555-1212	www.dwd.wisconsin.gov/dv_r	Statewide

Wishes

These organizations help provide wishes individuals with terminal illnesses in order to bring peace and improved quality of life to these.

Name	Contact	Website	Location
Dream Foundation	805-564-2131	www.dreamfoundation.org/dream-faq	Nationwide
Make a Wish	920-993-9994	www.wisconsin.wish.org	Nationwide

Writing your Legacy

One of the greatest gifts to future generations is to provide a written legacy for your loved ones and to impart your wisdom and memories for them to share. Journaling and legacy writing can also be therapeutic.

Name	Contact	Website	Location
Legacy Letter Project	Online	www.legacyletterproject.com/legacy.html	Nationwide
Emotional Legacy	Online	www.emotionallegacy.com/legacywriting1.htm	Nationwide

Books regarding writing your legacy:

Book Title	Author
The Legacy Guide	Carol Franco & Kent Lineback
How to Write Your Own Life Story	Lois Daniel
Writing Your Legacy: The Step by Step Guide to Crafting Your Life Story	Richard Campbell, MEd & Cheryl Svenson, PhD

Youth

Children and young adults are impacted by HD in various ways. There resources provide support in kid-friendly language for youth affected by HD.

Name	Contact	Website	Location
National Youth Alliance	Online	www.nya.hdsa.org	Nationwide
Huntington's Disease Youth Organization	Online	www.en.hdyo.org	International
HDSA- Contact the HDSA National Office as they have several publications dealing with children and juvenile onset HD	212-242-1968	www.hdsa.org	Nationwide