

HUNTINGTON'S DISEASE RESOURCES

STATE OF ILLINOIS

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Illinois CHAPTER

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Introduction

This document was created to provide information on resources in Illinois and nationwide for individuals and families affected by Huntington's Disease. This resource is for informational purposes only and does not constitute endorsement by HDSA.

Work in Progress

The resources in Illinois and nation-wide are ever-changing due to budget fluctuations and availability. Please contact the the Illinois HDSA chapter social worker, Emily Zivin at (630) 443-9876 or ezivin@hdsa.org if you have questions or need assistance. Additionally, if you have resources that have been helpful to you or someone you know in the HD community that you would like included for others to use, please contact Cori Robin.

Acknowledgment

Much gratitude and thanks goes to the Northwest and Northern California Chapters of HDSA, whose guides were used as a template for this current resource guide.

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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, especially those who are employed outside the home, and socialization for adults. Services offered in adult day service centers include health monitoring, medication supervision, personal care and recreational/therapeutic activities. Nutritious lunches and snacks are served and special diets are provided. Some day services may provide their own transportation. Find local adult day services below or call Social Worker for assistance.

Location	Name	Contact	Website
Statewide	Area Agency on Aging (AAA)	800-252-8966	www.state.il.us/aging/1directory/adult_day.pdf
Statewide	Illinois Adult Day Services Association	773-202-4130	www.iadsa.com
Nationwide	Elder Care Locator	Online	www.eldercare.gov/Eldercare.NET/Public/Resources/Factsheets/Adult_Day_Care.aspx

You have the right to make decisions about your health care now and in the future. Advanced directives are very powerful, as they allow you to prepare a written statement about how you want your medical decisions to be made in the future, should you no longer be able to make them yourself. You can find information on advanced directives, as well as free copies at the sites below:

Location	Name	Contact	Website
Statewide	Illinois State Medical Society's Advanced Care Planning Booklet	800-252-8966	www.isms.org/patients/Pages/personaldecision.aspx
Statewide	New POLST- Physician Orders for Life-sustaining Treatment	855-705-7845	/www.polst.org/
Nationwide	Caring Conversations	Online	/www.practicalbioethics.org/download-caring-conversations
Nationwide	Advance Care Planning	Online	www.acpdecisions.org/
Statewide	Illinois Department of Public Health	217-782-4977	www.idph.state.il.us/public/books/advin.htm
Nationwide	Five Wishes	888-594-7437	www.agingwithdignity.org/legal_Illinois.php
Statewide	Chicago End of Life Care Coalition	773-296-7247	/www.cecc.info/
Nationwide	Discussion starters	Online	www.mydirectives.com/en/Discussion-Guide
Nationwide	MedicAlert Foundation	888-633-4298	www.medicalert.org/services/adults
Nationwide	Compassion and Choices	800-247-7421	www.compassionandchoices.org/
Nationwide	Legal Guide for Chronic Illness	Online	www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_leg_gd_sersly_ill.authcheckdam.pdf
Nationwide	Toolkit for Advanced Healthcare Planning	Online	http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf

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Location	Name	Contact	Website
Nationwide	End of Life Decisions	Online	www.caringinfo.org/files/public/brochures/End-of-Life_Decisions.pdf
Nationwide	Conversations Before the Crisis	Online	www.caringinfo.org/files/public/brochures/Conversations_booklet.pdf
Nationwide	Artificial Nutrition and Hydration	Online	www.caringinfo.org/files/public/brochures/ArtificialNutritionAndHydration.pdf
Nationwide	Managing Someone Else's Money	Online	www.consumerfinance.gov/blog/managing-someone-elses-money/
Nationwide	HDSA Guide on Advanced Directives	Online	www.hdsa.org/images/content/1/9/19863/HDSA_Family%20Guide%20AdvanceDirectives%202013_FINAL.pdf

ADRN are local centers that act as a single point of entry for access to public long term support programs and public benefits. They provide information, referral and assistance as well as one-on-one options counseling to help people understand their long term care needs and make informed decisions about their services. ADRNs also offer Senior Health Assistance Program (SHAP), which provides counseling about Medicare benefits and prescription coverage available under Medicare Part D drug plans or Medicare Advantage plans that offer a prescription drug benefit and other pharmaceutical assistance programs. They provide application assistance as well.

Location	Name	Contact	Website
Illinois Department on Aging: Go here to locate your local Area Agency on Aging and they will connect you to the closest ARDN in your area	IL Dept on Aging	800-252-8966	http://www.cbrx.il.gov/aging/2aaa/aaa_list.htm#aaa6
Statewide	Aging and Disability Resource Center Locator	Online	www.adrc-tae.acl.gov/tiki-index.php?page=CordaMaps&st=IL
Statewide	PAS Center	Online	www.pascenter.org/state_based_stats/adrc.php?state=illinois
Nationwide	Administration for Community Living	Online	www.acl.gov/Programs/CDAP/OIP/ADRC/index.aspx#ADRC

The websites below have products available to make daily life skills slightly more manageable. Please browse the range of products such as devices for mealtime, bathing, dressing, toileting, etc.

Location	Name	Contact	Website
Nationwide	Able Data	Online	www.abledata.com/
Nationwide	Patterson Medical	Online	www.pattersonmedical.com/
Nationwide	Disability Products	Online	www.disabilityproducts.com/
Nationwide	Liftware- silverware that stabilizes tremor	Online	www.liftlabsdesign.com/
Nationwide	ALS Association	Online	www.alsa.org/als-care/resources/products/

If you are contemplating body or brain donation, please reach out to the following agencies to begin the consent and registration process. You may always change your mind, even after registering. Donations are much more difficult to process after someone has died so it is crucial to pre-plan ahead of time.

Location	Name	Contact	Website
Nationwide	Harvard Brain Tissue Resource Center	McLean Hospital 115 Mill Street Belmont, MA 800-272-4622	www.brainbank.mclean.org/
Statewide	Rush University Medical Center * Only accepts brains from those who are or have been Rush patients	312-563-2900 Or call brain bank clinic coordinator, Tracy Waliczek at 312-563-2848	www.rush.edu/rumc/page-R10021.html
Nationwide	Gift of Hope	Online	www.giftofhope.org/
Statewide	Anatomical Gift Association of Illinois	Online	http://agaillinois.org/

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

Name	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	Jim 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/living-with-huntingtons/publications/index.html
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

Caregiving is often a full time job, thus necessitating support for both the individual with HD as well as the caregiver. Resources below offer a variety of support services for free or at low cost: Short-Term Counseling, Support Groups, Professional Training, Legal and Financial Consultation and Education.

Location	Name	Contact	Website
Nationwide	Caring Voice Coalition	888-267-1440	www.caringvoice.org
Nationwide	HD Online Caregiver Support Group	Carmen@writerspeaker.com	www.writerspeaker.com/HDCaregivers.html
Nationwide	Family Care Navigator: State-by-State List from Family Caregiver Alliance	Online	www.caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083
Nationwide	Website for Rare Disease Caregivers	Online	www.rarecaregivers.org/
Statewide	Illinois Family Caregiver Support Program	800-252-8966	www.state.il.us/aging/1caregivers/program.htm#eligible
Statewide	Caregiver Resource Centers	800-252-8966	Locate your local center: www.state.il.us/aging/1caregivers/crc.htm
Nationwide	Caring From a Distance	Online	www.cfad.org/
Nationwide	Lotsa Helping Hands	Online	https://hdsa.lotsahelpinghands.com/info/
Nationwide	HDSA Support Groups	Online	www.hdsa.org/sg
Nationwide	HD Lighthouse	Online	www.hdlf.org
Statewide	Charism Elder Living Services	630-515-9223	http://charism.net/
Nationwide	E-book: After the Diagnosis	Online	http://www.caregiving.com/store/products/after-the-diagnosis/
Statewide	Primary Ally: Rebecca Murray	773-517-5864	www.primaryally.com

Care managers are usually social workers, psychologists, nurses, gerontologists or others with training and experience helping older adults or those with chronic illness to navigate the maze of care services. They can assess unique needs of the individual, handle crisis, help with care transitions, solve family disputes, attend doctor appointments, etc.

Location	Name	Contact	Website
Nationwide	Care Manager Locator	Online	http://memberfinder.caremanager.org/
Nationwide	Care Manager Locator	Online	www.caring.com/local/geriatric-care-managers
Statewide	Charism Elder Living Services	630-515-9223	http://charism.net/
Nationwide	Care Coordination	Online	http://nextstepincare.org/uploads/File/Guides/Care_Coordination/Care_Coordination.pdf
Statewide	LivHome	847-470-1703	www.livhome.com/
Statewide	Primary Ally: Rebecca Murray	773-517-5864	www.primaryally.com
Cook and Collar Counties	Creative Care Management	847-869-5118	www.creativecaremanagement.com/
Statewide	The Right Team	708-476-0996	www.therightteam.net/
Statewide	Lifecare Innovations	630-953-2154	www.lcius.com/
Statewide	Elder Care Consultants	773-508-1015	www.caregivinghelp.org/learn-about-us/your-eldercare-consultants
Statewide	SeniorBridge	866-506-1212	www.seniorbridge.com/
Statewide	Geriatric Care Consultants	847-295-3811	http://thegeriatriccareconsultants.com/
Statewide	Sanders and Warren	630-858-6466	www.sandersandwarren.com/

Therapy and counseling can be very helpful, as this helps an individual with coping, problem-solving, communication, grief/loss, stress management and other life stressors. There are many different types of counselors/therapists (LCSW, LCPC, LMFT, Psychologists) and it is important to choose a clinician whom you trust and with whom you feel comfortable. Social Worker is working on training psychotherapists in Illinois on aspects of HD. Please contact the social worker from HDSA should you want a specific referral for someone in your area.

Location	Name	Contact	Website
Nationwide	Psychology Today's directory of clinicians	Online	www.psychologytoday.com *Navigate your preferred choices
Anywhere	HD Internet Support Groups	Online	http://huntingtondisease.tripod.com/internetsupportgroups/
Nationwide	Find Counseling	Online	www.findcounseling.com/help/hotlines/illinois.html
Statewide	Illinois Community Mental Health Centers	800-843-6154 to locate a community mental health center near you	www.dhs.state.il.us/page.aspx?item=29728

Some counselors/therapists with HD knowledge are listed below. Social Worker is continuing to expand this list.

Location	Name	Contact	Website/Specialty
Arlington Heights, IL	Rebecca Kiel, LCPC	630-212-2090	http://rebeccakielpsychotherapist.blogspot.com/ chronic illness; caregiving support; sliding scale as needed
Batavia, IL	Mary McMillan, LCSW	630-399-2935	Sees patients in nursing homes; also accepts Medicare
Bloomington, IL	Samantha Wheeler, PhD	309-717-0819 x106 swheeler@psychologyspecialists.com	www.psychologyspecialists.com/ Chronic illness
Bloomington, IL	Trey Polesky, LCSW	773-819-5428	Sees patients with chronic and progressive health issues
Bourbonnais, IL	Life in Balance	866-787-4443	www.libhw.com/
Champaign, IL	Carla Cravens, LCSW	217-398-9066	Chronic illness; dementia; grief
Champaign, IL	Suzanne Martinez, LMFT	217-398-8100	www.cutherapist.com/
Champaign, IL	Nicholas Bridgett, LCSW	217-417-6432	Experience with caregiving
Champaign, IL	Sandy Colbs, PhD	309-228-4684	Chronic pain/illness; Grief/loss
Charleston, IL	Pam Miller, LCPC: Neuro Harmony	217- 508-7953	Neurofeedback/Biofeedback

Location	Name	Contact	Website/Specialty
Chicago, IL	Cori Robin, LCSW	crobin@urbanbalance.com	www.urbanbalance.com
Chicago, IL	Jennifer Medina, PhD	773-339-0621	www.jennifermedinaphd.com/
Chicago, IL	Lynne Kavin, LCSW	773-336-2579	Specializes in chronic illness www.lynnkavin.com/
Chicago, IL	Chicago Center for Family Health	312-372-4745	www.ccfhchicago.org
Chicago, IL	Sara Miller, LCPC	872-216-0384	www.abilityarts.com
Chicago, IL	Liza Guequierre, PsyD	312-380-9581	www.alliancecbt.com
Chicago, IL	Corina Teofilo Mattson, LMFT	312-477-0437	Spanish and English speaking; family therapy
Chicago, IL	David Ciesla, LCPC	312-208-9499	Relationships; anxiety; depression
Chicago, IL	Kirsten Belzer, LCSW	773-312-4859	Grief and loss; caregivers; children through adults; families and couples; Medicare
Chicago and Glen Ellyn, IL	Mary Kelleher, LMFT	312-252-9751	www.marykelleherlmft.com
Crystal Lake, Gurnee, Buffalo Grove & Hoffman	Arbor Counseling Center	847-913-0393	/www.arborcounselingcenter.com/
Dekalb, IL	Family Therapy Clinic of NIU	815-753-1684	Sliding Scale available
Dekalb, IL	Julie Ramisch, PhD	805-754-3514	Family; kids; grief/loss
Edwardsville and Alton, IL	Eve Kuckuck, ATR, LCPC	618-659-8787	Kids/teens- grief and loss www.nhbh.com/

Location	Name	Contact	Website/Specialty
Elgin, IL	Tracy Wright, LCPC	224-856-5988	www.renewedhopecounsel.com Sliding scale
Evanston/Northbrook, IL	Marcy LaKind, LCSW	847-840-8126	www.marcylakind.com
Evanston, IL	Mary Senn, LCSW	847-328-4074	www.marysenn.com/ Flexible fee option; works with caregivers and those with chronic illness
Evanston, IL	Sherrie All, PhD	855-COGWELL	www.cogwellness.com
Geneva, IL	Priscilla Brinkman, LCSW	630-471-2117	www.pbrinkman.com Flexible fee option; grief/loss; children, adults, families
Glen Carbon, IL	Jean McGurk O'Brien, LPC	618-980-2358	newleafcounselingservicesllc.yolasite.com/
Grayslake, IL	Therapy 4 Kids	773-315-3114	www.therapy4kidz.biz/
Hinsdale, IL	Marilee Feldman, LCPC	630-269-2886	www.marileefeldman.com
Hinsdale, IL	Nancee Biank, LCSW	630-655-9864	Children and family experiencing family illness www.nanceesplace.com
Joliet, IL	Midamerican Psychological- Tina Rago	815-735-0732	http://thempinstitute.com/ Sliding scale available
Kewanee, IL	Michele McShea, LCSW	773-653-5121	Grief/loss; relationship issues; anxiety
Lemont, Lisle and Chicago	Reem Cutinello, LCSW	630-777-7113	www.findingbalanceltd.com/
Lemont, IL	Susan Jacobowski, LCSW	630-257-5757	www.waterfallcounseling.com/
Lincoln, IL	Jennifer Imig Huffman, PhD	262-671-1494	Neuropsychologist specializing in movement disorders

Location	Name	Contact	Website/Specialty
Mendota and Rochelle, IL	Changes Counseling, LLC	815-562-2088	www.changescounselingllc.com/
Naperville, IL	Nowell & Associates	630-428-2344	www.nowellandassociates.org/
Oak Forest, IL	Anne Morrill-Ploum/Genesis	708-535-7320 x13	Children, young adults and families www.genesistherapy.org
Oak Park, Oak Brook and Chicago	Smart Love Family Services	708-660-4300	www.smartlovefamily.org/ For parents and children; Parent coaching/counseling
Oak Lawn, IL	Janhavi Desai, PhD	773-295-2893	www.southwestcaregroup.com/
Oak Lawn, IL and LaGrange, IL	Ankur Varma, M.A.	708-423-3361 x36	www.genesistherapy.org Sliding scale
Olympia Fields, IL	Mary Ann Riksheim	708-748-8309	www.marlcsw.com/
Quincy, IL	Janet Hay	217-653-5454	Grief counseling
Quincy, IL	Jerry Walker, LCPC	217-228-6194	www.jerrywalkertherapyservices.com/
Rockford, IL	Cynthia Kindgren, LCPC	815-397-2224	Counseling for neurological conditions
Schaumburg, IL and Vernon Hills, IL	Stuart Pinkwater, PsyD	847-932-0805	www.prapsych.com/ Specializes in chronic illness and its effects on family
Schaumburg, IL	Jennifer Budruweit, LPC	630-448-0658	www.lbcounseling.com/
Skokie, IL	Rachel Dubrow, LCSW	847-313-8074	www.racheldubrowlcsw.com/
Springfield, IL	Kay Gottrich, LCPC	217-726-9882	Health psychologist; Chronic illness; marriage and family therapy
Springfield, IL	Sandy McDermott, LCPC	217-787-0077	Hollistic/guided imagery; relaxation www.createtranquility.com/index.html#

Location	Name	Contact	Website/Specialty
Springfield, IL	Kristal Perry-Gutierrez, MA, LCPC	217-685-1639	Health related issues
Springfield, IL	Bahn and Associates	217-679-5379	www.bahnandassociates.com/
Sterling, IL	Dave Owens, LCSW	815-441-1152	Sliding scale; Relationships; relaxation; forgiveness
Sycamore, IL	Linda Benton, LCSW	815-219-4781	Medical social worker; sliding scale fee
Urbana, IL	Audrey Peppers, LCPC	217-619-0944	Children/chronic illness
Vernon Hills	Judy Shiffman, LCSW	847-361-2334	Chronic illness; caregiver issues
Washington, IL	Maggie Bagley, LCSW	309-472-7568	Medical psychology
Wilmette, IL	Rachel Prendergast, ATR, LCPC	847-687-1271	Art therapist and counselor
Winnetka, IL	Cathleen Margolin, PhD	847-508-7176	Chronic illness; relaxation techniques
Northern Cook, Lake, DuPage and Kane Counties (in-home)	In-Home Counseling: Nancy Wohlrabe	847-903-5604	www.inhomecounselingforseniors.com/
Cook county In-home counseling and Chicago	John Kalmus, LCSW	630-733-1796	Please call. Does in-home visits in Cook County.

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 Social Worker for additional resources and referrals.

Location	Name	Contact	Website
Nationwide	Reproductive Genetics Institute	773-472-4900	www.reproductivegenetics.com/
Nationwide	Stanford HOPES Family Planning Resources	Online	www.stanford.edu/group/hopes/cgi-bin/wordpress/2011/07/family-planning/
Nationwide	HD Free with PGD	Online	www.hdfreewithpgd.com/
Nationwide	Protected Tomorrows- Future Care planning re: education, residential, financial, legal, healthcare, benefits, employment and recreation	847-522-8086	www.protectedtomorrows.com/
Nationwide	Having a Family ,The HD Way from HD Buzz	Online	http://en.hdbuzz.net/036

There are programs that provide free cell phones and calling plans to individuals who qualify. If you receive other benefits, such as SNAP or Medicaid, you may be eligible.

Location	Name	Contact	Website
Nationwide	Safelink Wireless	800-723-3546	www.safelinkwireless.com
Nationwide	Lifeline phone assistance	888-641-8722	http://tinyurl.com/l3jq3lf
Nationwide	Reachout Wireless	877-870-9444	www.reachoutmobile.com

Applying for financial benefits can be a long and frustrating process. However, the resources below may be able to assist in obtaining application information and forms as well as answer questions about specific financial programs.

Location	Name	Contact	Website
Nationwide	Benefits Checkup	Online	www.benefitscheckup.org/
Nationwide	PowerWallet Money Management	Online	www.powerwallet.com/
Nationwide	Social Security Disability	800-772-1213	www.ssa.gov/applyfordisability/
Nationwide	Calculator to Check Your Estimated Social Security Benefits	Online	www.socialsecurity.gov/planners/benefitcalculators.htm
Nationwide	SSDI Help	Online	www.socialsecurity-disability.org/
Nationwide	SSDI Tips	Online	www.hdsa.org/living-with-huntingtons/family-care/disability.html
Nationwide	HDSA Disability Toolkit	Online	www.hdsa.org/disability
Statewide	State Benefit Programs	Online	www.benefits.gov/benefits/browse-by-state/state/IL
Statewide	CEDA- emergency help for vision, dental, healthcare	312-795-8955	www.cedaorg.net/www2/CDS.html
Statewide	Medicaid Integrated Care Program	Online	www2.illinois.gov/hfs/ManagedCare/Pages/ICPGuide.aspx
Statewide	Changes to Medicaid benefits	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/ChangesStateMedicalBenefits.pdf

Applying for financial benefits can be a long and frustrating process. However, the resources below may be able to assist in obtaining application information and forms as well as answer questions about specific financial programs.

Location	Name	Contact	Website
Statewide	Your Benefits Advocate- Susan Loeb	773-684-9802	www.yourbenefitsadvocate.com/
Statewide	Envision Benefits- Lori Martin	708-243-5768	www.envision-benefits.com/
Nationwide	Allsup-SSDI representation	800-279-4357	www.allsup.com/
Nationwide	Protected Tomorrows	847-522-8086	www.protectedtomorrows.com
Nationwide	Jan L. Kodner & Associates	312-922-6688	www.mysocialsecuritylawyer.com
Statewide	Common Medicaid Mistakes	Online	http://tinyurl.com/9we2eqc
Statewide	Wells Fargo- Trust and Fiduciary Specialist- Allison Getz	312-592-5629	www.wellsfargo.com/investing/investmentservices/trust/
Nationwide	American Association of Daily Money Managers	877-326-5991	www.aadmm.com/
Nationwide	Ehlert Financial Group	Online	www.ehlertfinancialgroup.com/Services/SpecialNeedsPlanning/item33395.html
Nationwide	Free Budgeting Assistance with Green Path	Online	http://tinyurl.com/l6ooc6f

Proactive planning for financial and legal security is extremely important in families affected by HD.

Location	Name	Contact	Website
Nationwide	MetLife Special Needs Planners Tim Dunneback Jeffrey Schanerman Irv Birnbaum	TD-630-441-1029 JS- 219-738-5646 IB- 773-725-4167	www.metlife.com/individual/planning/special-needs/index.html?WT.ac=GN_individual_planning_special-needs#basic-steps
Statewide	Envision Benefits- Lori Martin	708-243-5768	www.envision-benefits.com/
Nationwide	Protected Tomorrows	847-522-8086	www.protectedtomorrows.com
Nationwide	Jan L. Kodner & Associates	312-922-6688	www.mysocialsecuritylawyer.com
Statewide	Wells Fargo- Trust and Fiduciary Specialist- Allison Getz	312-592-5629	www.wellsfargo.com/investing/investmentservices/trust/
Nationwide	American Association of Daily Money Managers	877-326-5991	www.aadmm.com/
Nationwide	Ehlert Financial Group	Online	www.ehlertfinancialgroup.com/Services/SpecialNeedsPlanning/item33395.html

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

Location	Name	Contact	Website
Nationwide	Supplemental Nutrition Assistance Program (SNAP)	800-843-6154	https://abe.illinois.gov/abe/access/
Nationwide	Feeding America- Locate your local food bank	800-771-2303	http://feedingamerica.org/foodbank-results.aspx
Nationwide	Emergency Food Assistance Program (TEFAP)	217-782-1317	http://tinyurl.com/k7unxaz
Chicago only	Commodity Supplemental Food Program (CSFP)	217-524-3354	http://tinyurl.com/pbxdwed
Statewide	Feeding Illinois	Online	www.feedingillinois.org/
Statewide	Food Pantries in Illinois	Online	www.foodpantries.org/st/illinois
Statewide	Solve Hunger Today	Online	http://solvehungertoday.org/GetHelp/IllinoisFoodBanks.aspx
Statewide	Illinois Food Connections	Online	www.dhs.state.il.us/page.aspx?item=31245
Statewide	Chicago Greater Food Depository	773-247-3663	www.chicagosfoodbank.org/site/PageServer?pagename=member_need_food

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 grieve, but seeking the support of others can be beneficial for you. Below are some grief and loss resources to explore. To locate support groups specifically in your area, please contact Social Worker.

Location	Name	Contact	Website
Nationwide	Funeral/Arrangement Planning- My Way Forward	Online	www.mywayforward.com/
Nationwide	Death for Beginnings- Planning Guide	Online	http://deathforbeginners.com
Statewide	Pre-need Funeral and Burial Guide	Online	www.ioc.state.il.us/index.cfm/departments/cemetery-care/forms-and-downloads/illinois-funeral-or-burial-consumers-guide/
Nationwide	Planning a Funeral	Online	http://nfda.org/planning-a-funeral.html
Statewide	Illinois Funeral Directors Association	Online	http://ifda.org/illinois-consumer-guide/
Statewide	Pre-Planning FAQ	Online	http://ifda.org/pre-planning-faqs/
Nationwide	The Light Beyond	Online	www.thelightbeyond.com/funeral_pre-planning_a_practical_matter.html

Genetic testing for HD presents people at risk for the disease with a difficult choice, given the current absence of an effective treatment or cure. The decision to test or not test 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 Social Worker should you want to discuss further or want to process this difficult decision.

Location	Name	Contact	Website
Statewide	Rush University Medical Center HDSA Center of Excellence	1725 W. Harrison Chicago, IL 312- 942-5003	https://www.rush.edu/services/conditions/huntingtons-disease
Statewide	Northwestern Medicine HDSA Center of Excellence	675 North St. Claire, Chicago, IL 312 695-7950	https://www.nm.org/conditions-and-care-areas/neurosciences/parkinsons-disease-and-movements-disorders/huntingtons-disease
Statewide	Advocate Lutheran General Hospital	1875 Dempster St. Park Ridge, IL 847-723-7705	www.advocatehealth.com
Statewide	Central DuPage Hospital Movement Disorders Center	Dr. Martha McGraw 630-933-4056	www.cdh.org/Find-A-Doctor-Profile.aspx?id=6741
Nationwide	GINA (Genetic Non Discrimination Act):	Online	www.genome.gov/24519851
Nationwide	HDSA GINA Toolkit	Online	www.hdsa.org/gina
Nationwide	Personal Essays on Genetics and Identity: Book on Genetic Disorders/Testing	Online	http://jhupbooks.press.jhu.edu/ecom/MasterServlet/GetItemDetailsHandler?iN=9781421410968&qty=1&source=2&viewMode=3&loggedIN=false&JavaScript=y

Know your rights regarding GINA: Genetic Information Non-Discrimination Act, which created protections against the misuse of peoples' genetic information by health insurance and employers. Please consult a genetic counselor and/or social worker before and after testing.

Location	Name	Contact	Website
Worldwide	Know your Rights	Online	www.respondgeneticdiscrimination.com/
Nationwide	Gina Help	Online	www.ginahelp.org/
Nationwide	HD and GINA	Online	www.hdsa.org/living-with-huntingtons/family-care/living-at-risk/gina-information.html
Nationwide	Coalition for Genetic Fairness	Online	www.geneticfairness.org/GINAPublication111008.pdf

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Location	Name	Contact	Website
Statewide	Rainbow Hospice Grief and Loss Center (many types of grief groups and in several languages)	847-692-8884	www.rainbowhospice.org/grief_and_loss/groups_workshops/
Statewide	Center for Grief Recovery	773-274-4600	www.griefcounselor.org
Statewide	Youth Grief Groups	Online	www.dougy.org/grief-support-programs/
Statewide	Hello Grief	Online	www.hellogrief.org/resources/illinois/
Statewide	Good Mourning Children's Grief Program	Online	www.rainbowhospice.org/grief_and_loss/good_mourning/
Statewide	LOSS: Loving Outreach to Survivors of Suicide	Online	www.catholiccharities.net/loss
Nationwide	Open to Hope	Online Support Forum	www.opentohope.com/
Nationwide	No Wrong or Right Way to Grieve	Online	www.caringinfo.org/files/public/brochures/There is no Wrong or Right Way to Grieve After a Loss.pdf

Guardianship is a court order granting someone the legal authority to be in charge of a 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.

Location	Name	Contact	Website
Statewide	Illinois Guardianship and Advocacy Commission	Online	http://gac.state.il.us/guardfaq.html
Nationwide	National Guardianship Network	Online	www.nationalguardianshipnetwork.org
Nationwide	National Guardianship Association	Online	www.guardianship.org
Nationwide	ABA Commission on Law and Aging	Online	www.americanbar.org/groups/law_aging/resources/
Nationwide	Center for Elders and the Courts	Online	http://eldersandcourts.org
Nationwide	National Academy of Elder Law Attorneys	Online	www.naela.org/Public/About_NAELA/Public_or_Consumer/Guardianship.aspx
Statewide	Illinois Legal Aid	Online	http://tinyurl.com/ln89lny

The clinics listed below offer health and medical support for patients with HD. Please call the clinic directly to obtain information or schedule an appointment. Please also contact your health insurance to identify if the clinics below are covered under your plan. If you would like your local PCP or neurologist to learn more about HD, please have them call Social Worker for more education/information.

Location	Name	Contact	Website
Chicago, IL	HDSA Center of Excellence at Rush University Medical Center	Dr. Jennifer Goldman- neurologist 312-563-2900	www.rush.edu/rumc/page-R11685.html
Chicago, IL	HDSA Center of Excellence and Northwestern Medicine	Dr. Danny Bega - neurologist 312 695-7950	https://www.nm.org/conditions-and-care-areas/neurosciences/parkinsons-disease-and-movements-disorders/huntingtons-disease
Rockford, IL	University of Illinois College of Medicine	Dr. Mitch King- 815-972-1000	www.rockford.medicine.uiowa.edu/
Peoria, IL	Illinois Neurological Institute	Dr. Lamichange: Movement Specialist; 309-624-8500	http://m.ini.org/services/movement-disorders-center/
Winfield, IL	Central DuPage Hospital Movement Disorders Center	Dr. Martha McGraw 630-933-4056 Nurse: Mary Pat Ostrander: 630-933-4243	www.cdh.org/Find-A-Doctor-Profile.aspx?id=6741
Nationwide	HD Physician's Guide	Online	www.hdsa.org/images/content/1/6/16692/HDSAPhysDeskRef_11_web.pdf

There is a wealth of information on HD online. In order to ensure that the information is legitimate, please visit the below sites.

Location	Name
HDSA HD Trial Finder	http://www.hdtrialfinder.org
European Huntington's Disease Network	www.euro-hd.net
CHDI Foundation, Inc	www.chdi-inc.org
HD Buzz- HD research in real person's language!	www.Hdbuzz.net
Huntington Study Group	www.huntington-study-group.org
HD Drug Works	www.Hddrugworks.org
HD: Hope Through Research: National Institute of Neurological Disorders and Strokes	www.ninds.nih.gov/disorders/huntington/detail_huntington.htm
Stanford Hopes	www.stanford.edu/group/hopes/cgi-bin/wordpress/
Past Editions of Towards a Cure	www.hdsa.org/living-with-huntingtons/publications/ptac.html
Past Editions of The Marker	www.hdsa.org/living-with-huntingtons/publications/pmark.html

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

Name	Contact	Website
Huntington's Disease Society of America (HDSA)	505 Eighth Ave, St 902 New York, NY 10018 800-345-4372	www.hdsa.org
HD Articles Divided by Topic	Online	www.hdsa.org/archive
Mayo Clinic Huntington's Information	On-line	www.mayoclinic.com/health/huntingtons-disease/DS00401
HD Advocacy Center	On-line	www.hdac.org
HD Lighthouse	On-line	www.hdlighthouse.org
Huntington's Dance	On-line	www.huntingtonsdance.org/
Huntington's Outreach Project for Education at Stanford (HOPES)	On-line	www.hopes.stanford.edu
We are HDSA	On-line	www.hdsa.org/living-with-huntingtons/publications/wearehd.html
HD Centers of Excellence	On-line	www.hdsa.org/living-with-huntingtons/resources/centers-of-excellence/index.html
HSG: Huntington Study Group	On-line	www.huntington-study-group.org/
HD Buzz	On-line	www.hdbuzz.net/
HD Drug Works	On-line	www.hddrugworks.org/
HDYO	On-line	www.en.hdyo.org/

Home health care services provide a range of medical services in a home setting such as physical therapy, speech therapy, occupational therapy, medication 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 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.

Location	Name	Contact	Website
Nationwide	National Association for Home Care and Hospice	Online 202-547-7424	www.nahcagencylocator.com/
Nationwide	Home Health Compare: U.S. Dept of Health and Human Services, Centers for Medicare and Medicaid Services	800-633-4227	www.medicare.gov/homehealthcompare/search.aspx
Statewide	CJE Home Safety Assessment	773-508-1000	www.cje.net/support-services/home-safety-assessment-service
Nationwide	Care Centrix	Online	www.carecentrix.com/
Statewide	Memory Care Corp- Speech Therapy and Occupational Therapy	630-800-2444	www.memorycarecorp.com/index.html
Nationwide	American Academy of Home Care Medicine (house calls)	410-676-7966	www.aahcm.org/?Locate_A_Provider

People with disabilities who plan to stay in the home, if possible, 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.

Location	Name	Contact	Website
Nationwide	Independent Living Solutions	773-478-8450	www.ilsremodel.com/accessibility-services/
Nationwide	Extended Home Living Services	847-852-7988	www.ehls.com/
Statewide	Leslie M. Stern Design	773-248-2049	www.lesliemsterndesign.com/special_needs.php
Nationwide	List of Home Modification Funding Sources	Online	www.disabilityrights.org/mod3.htm
Nationwide	Ramp Up	708-444-8460 x231	www.ucpnet.org/access-ramp-up.php
Chicago	HomeMod Program through Mayor's Office for People with Disabilities		www.cityofchicago.org/city/en/depts/mopd/provdrs/hous/svcs/accessible_home_modificationprogram-ages0-5911.html
Illinois and Wisconsin	Bridgeway Independent Living Designs	847-453-8866	www.bildnow.com/
Illinois and Indiana	Access	630-616-6249	www.accesslevator.net/
Nationwide	Abilities 365	Online	www.abilities365.com/

Hospice and Palliative Care offers services and therapies to patients who are in later stages of HD and help the patient 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 patients. Please contact Social Worker for referrals in your local area.

Location	Name	Contact	Website
Nationwide	National Hospice and Palliative Care Organization	Online	www.nhpco.org
Nationwide	Hospice Directory	Online 800-854-3402	www.hospicedirectory.org
Nationwide	American Hospice Foundation	Online	www.americanhospice.org/
Nationwide	American Academy of Hospice and Palliative Medicine	Online	www.aahpm.org/
Nationwide	Questions to Ask Hospice Providers	Online	www.caregiverslibrary.org/Portals/0/ChecklistsandForms_QuestionsAboutHospiceCare.pdf
Nationwide	Ever Plans	Online	www.everplans.com/
Nationwide	Get Palliative Care	Online	www.getpalliativecare.org/
Statewide	Illinois Hospice and Palliative Care Organization	Online	www.il-hpco.org/
Nationwide	Caring Connections	Online	www.caringinfo.org/
Nationwide	Compassion and Choices	Online	www.compassionandchoices.org/
Nationwide	Aging with Dignity	Online	www.agingwithdignity.org/
Nationwide	Center to Advance Palliative Care	Online	www.capc.org/

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Location	Name	Contact	Website
Statewide	Guiding Light	773-403-0933	www.guidinglighthospice.com/
Statewide	Midwest Palliative and Hospice Care	Online	www.carecenter.org/
Statewide	Rainbow Hospice	Online	www.rainbowhospice.org/
Statewide	Angels Grace Hospice	Online	www.angelsgracehospice.com/
Nationwide	Heartland Hospice	866-231-5695	www.heartlandhospice.com/

Housing: Placement agencies/Locating Facilities in Your Area³⁹

Placement agencies can help in locating facilities in your area that will meet your caregiving needs. The process usually includes an intake and assessment to determine care needs and financial eligibility. Some agencies offer the services free of charge, while others may charge an hourly fee. Please call Social Worker for assistance in locating an appropriate living community for you or your loved one.

From Dr. Jane Paulsen's Understanding Behavior in HD (2000): One family was confronted with resistance from their family member, Helen, when it came time to discuss the topic of placement in a skilled nursing facility. Helen's family was not confrontational with her. They simply shifted the discussions over a several-month period from "if you need to be placed" to "when you need to be placed" to "it's getting to be the time you will need to move into a facility" to "Where you are going to live is an important decision and I do not want to make it without you. I have found four places I want you to see." Placement was discussed at various times from the beginning of the disease, so the topic was not a surprise. Although there was some argument when the time came, Helen was given time to process the change as well as the power to choose the facility (pg. 16).

Location	Name	Contact	Website
Nationwide	Nursing Home Compare: US Dept of Health and Human Services	Online	www.medicare.gov/NursingHomeCompare/ * Locate and compare quality ratings
Statewide	US News Best Nursing Homes	Online	http://health.usnews.com/best-nursing-homes/area/il
Nationwide	Medicaid and Long Term Care	Book	www.hdsa.org/images/content/2/1/v2/21164/Medicaid-and-LTC-Handbook.pdf
Statewide	Illinois Peer Coalition	Online	www.illinoispioneercoalition.org/your-way.php
Statewide	Elderwerks	847-877-8215	www.elderwerks.com
Statewide	A Place for Mom	877-666-3239	A free referral service helping families find nursing homes, assisted living, retirement communities, home care and other living options. www.aplaceformom.com
Statewide	IL Department of Public Health	Online	www.idph.state.il.us/healthca/nursinghometestjava.htm
Statewide	IL Council on Long Term Care	773-478-6613	www.nursinghome.org/how.html
Statewide	Illinois Citizens for Better Care-nursing home advocates	312-663-5120	www.illinoiscares.org/factsheet.html

Assisted Living is for people who are fairly independent but require some daily supervision and assistance with house chores and personal care. These facilities may offer rooms or apartment-style accommodations and often include social activities. Meals are provided. Staff can help with daily needs such as bathing, grooming, eating or using the toilet. The monthly charge is determined by how much care is required. Supportive Living is a more affordable option administered by the Department of Healthcare and Family services. The aim of this program is to preserve autonomy while emphasizing health and wellness for people who would otherwise need nursing facility care.

Location	Name	Contact	Website
Statewide	Illinois Supportive Living Program	Online	www.sfillinois.com/factsheetresident.html
Statewide	Assisted Senior Living	Online	www.assistedseniorliving.net/services/illinois/
Statewide	Eden Supportive Living: provides supportive living to people with disabilities age 22-64	773-572-6485	www.edensupportiveliving.com/
Statewide	Deer Path Supportive Living for people age 22-64	847-515-1800	www.bma-mgmt.com/deerpathhuntley/
Chicago	Chicago Central Referral System Assessment for Supportive Housing	Online	www.chicagocrs.org
Nationwide	Care Pathways	Online	www.carepathways.com/

The following list of skilled nursing facilities/nursing homes have had a person with HD or have shown some willingness to care for a resident with HD. Inclusion in this list does not constitute endorsement as management often changes. Please check their quality rating on www.medicare.gov/nhcompare and always visit first, unannounced, to observe how the living community is run.

Location	Name	Contact	Website
Nationwide	LTC Guide for HD	Online	http://www.hdsa.org/images/content/1/4/14768.pdf
Illinois	Barton Health Care	Multiple sites: see online	http://www.bartonhealthcare.org
Aledo, IL	Aledo Nursing & Rehab	309-582-5376	www.petersenhealthcare.net/aledo/
Alton, IL	Alton Rehab and Nursing Center	618-465-8887	Please call
Anderson, IN	Edgewater Woods	765-644-0903	www.ascseniorcare.com/edgewater-woods/
Arcola, IL	Arcola Healthcare & Rehab	217-268-3022	www.petersenhealthcare.net/arcola/
Arlington Heights, IL	Manor Care	847-392-2020	http://www.heartland-manorcare.com/locations/manorcare-at-arlington-heights/
Aurora, IL	Jennings Terrace	630-897-6947	www.jenningsterrace.com/
Aurora, IL	North Aurora Care Center	630-892-7627	www.petersenhealthcare.net/north-aurora/
Aviston, IL	Aviston Countryside Manor	618-228-7615	www.avistoncountrysidemanor.com/
Batavia, IL	Batavia Rehab and Healthcare	630-879-5266	www.petersenhealthcare.net/batavia/
Bloomington, IL	West Suburban Nursing and Rehab	630-894-7400	www.wsnrc.com/
Brighton, IL	Robings Manor	618-372-3232	www.petersenhealthcare.net/robings-manor/

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Location	Name	Contact	Website
Burnsville, MN	Sonshine and Hope Home for HD	952-435-0909	www.sonshineandhope.com/
Cloverdale, IN	Summerfield Healthcare Nursing Home	765-795-4260	http://summerfieldhealthcarecenter.com
Chicago, IL	Bethesda Home	773-622-6144	www.bethesdahome.com/
Chicago, IL	Buckingham Pavilion	773-973-5333	www.buckinghampavilion.com/
Chicago, IL	Warren Park Health & Living Center	773-465-5000	warrenparkrehab.com/
Chicago, IL	Arbour Healthcare Center	773-465-7751	www.arbourhealthcare.com/
Chicago, IL	All American Nursing Home	773-334-2224	www.allamericannursing.com/
Chicago, IL	Clark Manor Convalescent Center	773-338-8778	http://www.clarkmanorchicago.com
Chicago, IL	Norwood Crossing	773-577-5323	www.norwoodcrossing.org/
Chicago, IL	Parkshore Estates	773-752-6000	Please call
Chicago, IL	Waterford Nursing and Rehab	773-338-3300	Please call
Chicago, IL	Wesley Place	773-769-5500	Please call
Chicago, IL	Sheridan Shores	773-769-2230	sheridanshores.com/
Cicero, IL	Alden Town Manor	708-863-0500	http://www.aldentownmanor.com
Columbus, OH	Bryden Place	614-258-6623	Please call
Effingham, IL	Evergreen Nursing and Rehab	217-347-7121	http://evergreennursingrehab.com

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Location	Name	Contact	Website
Eldorado, IL	Fountain View	618-273-3353	http://www.fountainviewinc.com/index.html
Ellettsville, IN	Richard-Blossom Health Care	812-876-6400	http://www.rbbhcc.com
Ellettsville, IN	Richard-Blossom Health Care	812-876-6400	http://www.rbbhcc.com
Evanston, IL	The Grove of Evanston	847-316-3320	www.thgroveofevanston.com
Fort Wayne, IN	Byron Health Care	260-637-3166	https://byronhealth.org
Gas City, IN	Twin City Nursing Home	765-674-8516	www.twincity-healthcare.com/
Highwood, IL	Highland Park Nursing and Rehab	847-432-9142	http://hpnrc.com/
Kenosha Estates Living and Care Center	Kenosha, Wisconsin	262-658-4125	http://www.kenoshaestatesrcc.com
Kewanee, IL	Royal Oaks Care Center	309-857-3389	https://www.petersenhealthcare.net/royal-oaks/
Knoxville, IL	Knox County Nursing Home	309-289-2338	Please call
Lake Zurich, IL	Lexington Health	847-726-1200	www.lexingtonhealth.com/
Lewistown, IL	Prairie View	309-547-2267	www.chmcare.com/lewistown/
Libertyville, IL	Winchester House	847-377-7200	www.winchesterhouse.com
Lindenhurst, IL	Village at Victory Lakes	847-356-4666	https://www.franciscanministries.org/victory-lakes/

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Location	Name	Contact	Website
Long Grove, IL	Alden Long Grove	847-4388275	www.aldenlonggrove.com/
Mattoon, IL	Palm Terrace	217-234-7403	www.petersenhealthcare.net/palm-terrace/
Mendon, IL	North Adams Home	217-936-2137	www.northadamshome.org/
Moline, IL	Heartland	309-764-6744	Please call
Naperville, IL	Alden Estates	630-983-0300	www.aldenstatesofnaperville.com/
Naperville, IL	St. Patrick's Residence	630-416-6565	www.stpatricksresidence.org/
Niles, IL	Niles Nursing and Rehab Center	847-967-7000	www.nilesnursing.com/
North Aurora	North Aurora Care Center	630-892-7627	https://www.petersenhealthcare.net/north-aurora/
Orland Park, IL	Alden Estates	708-403-6500	www.aldenstatesoforlandpark.com/
Palos Park, IL	Sunrise	708-361-3577	www.sunriseseniorliving.com
Peoria, IL	Sharon Healthcare Pines	309-264-6100	www.sharonhealthcarepines.com/
Peoria, IL	Sharon Healthcare Willows	309-688-2457	http://shcwillows.org/contact-us/
Pine City, MN	HD Hobby Farm	320-629-6245	http://hdcountrycare.com/

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Location	Name	Contact	Website
Prophetstown	Winning Wheels	815-537-5168	www.winningwheels.com/
Richmond, MN	Tadd's Lighthouse	320-597-2661	http://taddslighthouse.com/
Robbinsville, MN	University of Good Samaritan	612-673-6260	www.good-sam.com/index.php/locations/specialtycarecommunity
Rock Falls, IL	Rock Falls Rehabilitation	815-626-4575	https://www.petersenhealthcare.net/rock-falls/
Rockford, IL	Alden Park Strathmoor	815-229-5200	www.aldenparkstrathmoor.com
Rolling Meadows, IL	Clearbrook ICF	847-385-5018	www.clearbrook.org/
Rosiclare, IL	Rosiclare Nursing & Rehab	618-285-3655	www.petersenhealthcare.net/rosiclare/
Sheldon, IL	Sheldon Healthcare Center	815-429-3134	www.petersenhealthcare.net/sheldon/
Skokie, IL	The Grove of Skokie	847-679-2322	http://thegroveofskokie.com
Sterling, IL	Regency Care of Sterling	815-626-9020	Call for information.
Sterline	Rock River Gardens	815-626-2333	https://www.petersenhealthcare.net/rock-river/
Vernon Hills, IL	Brookdale Assisted Living	847-440-3766	https://www.brookdale.com/en/communities/brookdale-vernon-hills.html
Wheaton, IL	DuPage Convalescent Center	630-665-6400	www.dupageco.org/Convalescent_Center/6086/

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

Location	Name	Contact	Website
Statewide	Medicaid	Online	www.hfs.illinois.gov/html/061512n.html
Statewide	Shield Healthcare	800.675.8847	www.shieldhealthcare.com/
Statewide	Simon Foundation Diaper Bank	Online	www.simonfoundation.org/Diaper_Banks.html
Statewide	Home Products for Seniors	800-425-1101 x 103	http://homeproductsforseniors.com/

In-home help involves personal care (dressing, grooming, bathing), companionship, housekeeping, personal care, grocery shopping, etc. This service is usually provided on an hourly basis and is not covered by health insurance. Most agencies will charge around \$15-25 per hour but rates vary by agency. If you are under a certain asset limit, there may be avenues through the Department of Human Services or the Department on Aging that can assist with payment. Please call Social Worker for assistance and local referrals.

Location	Name	Contact	Website
Nationwide	Home Care: A Family Caregiver's Guide	Publication	http://nextstepincare.org/uploads/File/Guides/Home_Care/Guide/Home_Care.pdf
Nationwide	Working with Home Health Aides	Publication	http://nextstepincare.org/uploads/File/Guides/Home_Care/Home_Health_Aides/Working_with_Home_Health_Aides.pdf
Statewide	Home Services Program through Department of Human Services	800-843-6154	www.dhs.state.il.us/page.aspx?item=29738 (under 60 yrs old and financially eligible)
Statewide	Community Care Program through Department on Aging	800-252-8966	www.state.il.us/aging/1athome/ccp.htm (Over 60 and financially eligible)
Nationwide	Right at Home	877-697-7537	www.rightathome.net/states/illinois/
Nationwide	Comfort Keepers	800-387-2415	www.comfortkeepers.com/
Nationwide	Home Instead	800-640-3914	www.homeinstead.com/Pages/home.aspx
Statewide	Services for Adults Staying in Their Homes (SASI)	847-864-7274	www.sasiathome.org/
Statewide	Wellspring Personal Care	312-648-1565	http://homecarechicago.com/
Nationwide	Care Pathways	Online	www.carepathways.com/
Statewide	Companions for Seniors	866-910-9020	http://companionsforseniors.com/

Resources below may help with obtaining application information to apply for various insurance benefits.

Location	Name	Contact	Website
Statewide	Get Covered Help- free assistance	Online	http://getcoveredillinois.gov/get-help/
Statewide	Health Insurance Marketplace	Online	www.healthcare.gov
Nationwide	Cost of insurance plan calculator	Online	http://kff.org/interactive/subsidy-calculator/
Nationwide	Info on Healthcare Reform	Online	http://marketplace.cms.gov/getofficialresources/publications-and-articles/publications-and-articles.html
Statewide	Healthcare Reform in Illinois	Online	www2.illinois.gov/gov/healthcarereform/Pages/default.aspx
Statewide	Illinois Health Matters	Online	http://illinoishealthmatters.blogspot.com/
Statewide	Illinois Health Care Options	Publication	www.coverageforall.org/pdf/matrix/IL_Matrix.pdf
Cook County, IL	County Care	312-864-8200	http://countycare.com/
Nationwide	Medicare	800-772-1213	www.medicare.gov
Nationwide	Family Medical Leave Act	866-487-9243	www.dol.gov/whd/fmla/
Nationwide	Patient Advocate Foundation	Online	www.patientadvocate.org/index.php
Nationwide	Health and Disability Advocates	312-223-9600	www.hdadvocates.org/index.asp
Statewide	Illinois Pre-Existing Condition Insurance Plan (IPXP)	877-210-9167	www.insurance.illinois.gov/ipxp/
Nationwide	SSDI vs SSI	800-843-6154	http://tinyurl.com/c5mojxn
Nationwide	Medicare Parts C and D info	Online	www.medicare.gov/Pubs/pdf/11219.pdf

Resources below may help with obtaining application information to apply for various insurance benefits.

Location	Name	Contact	Website
Nationwide	Learning about Health Insurance	Online	http://marketplace.cms.gov/help-us/c2c-roadmap.pdf
Statewide	Illinois Long Term Care Insurance Partnership	800-252-8966	www.completelongtermcare.com/states/illinois/
Nationwide	American Association for Long Term Care Insurance	818-597-3227	www.aaltci.org/long-term-care-insurance/
Statewide	Illinois Department of Insurance	217-782-4515	www.insurance.illinois.gov/
Statewide	Illinois Health Matters	Online	http://illinoishealthmatters.org/
Statewide	Your Benefits Advocate- Susan Loeb	773-684-9802	www.yourbenefitsadvocate.com/
Nationwide	Jan L. Kodner & Associates	312-922-6688	www.mysocialsecuritylawyer.com
Statewide	Resources for people 55-64 yrs without insurance	Online	www.ageoptions.org/whatwedo/documents/FINALPreMedicareToolkit.7.10.12.pdf
Statewide	Common Medicaid Mistakes	Online	http://tinyurl.com/9we2eqc
Nationwide	Affordable Care Act Tipsheets	Online	www.ageoptions.org/services-and-programs_AffordableCareActTipSheets.html
Nationwide	Extra Help Program	800-772-1213	www.ssa.gov/prescriptionhelp/
Nationwide	Medicare Savings Program	800-843-6154	http://tinyurl.com/khc5upv
Nationwide	Same Sex Couples	Online	http://blog.sageusa.org/blog/2014/06/medicare-the-windsor-decision-where-do-we-stand-.html

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

Location	Name	Contact	Website
Nationwide	Patient Advocate Foundation	Online	www.patientadvocate.org/index.php
Nationwide	Legal Planning Guide	Online	www.caringinfo.org/files/public/brochures/Legal_Guide_for_Seriously_Ill.pdf
Statewide- Cook Co.	Center for Disability and Elder Law	312-376-1880	www.cdela.org
Nationwide	Health and Disability Advocates	312-223-9600	www.hdadvocates.org/client_serv/
Statewide	Equip for Equality	312-223-9600	www.equipforequality.org/programs/
Statewide	Illinois Guardianship and Advocacy Commission	866-274-8023	www.gac.state.il.us/
Statewide	Law Elder Law, LLP- Attorneys for eldercare, estate planning, etc	800-810-3100	www.lawelderlaw.com/
Statewide	Teresa Nuccio- Attorney for estate planning and special needs	847-823-9576	www.teresanuccio.com/
Statewide	Dutton and Casey- Elder Law/ Special Needs Attorneys	Erin Vogt (social worker): 312- 899-0950	www.duttonelderlaw.com/
Statewide	Heartland Law	847-729-3300	www.heartlandlawfirm.com/
Statewide	Bill Wilson Elder Law	708-482-7090	www.lagrangelaw.com/
Statewide	Your Benefits Advocate- Susan Loeb	773-684-9802	www.yourbenefitsadvocate.com

Location	Name	Contact	Website
Statewide	Peck and Bloom, LLC	877-845-1743	www.peckbloom.com/
Statewide	Chicago Volunteer Legal Services	312-332-1624	www.cvls.org/
Statewide	Chicago Legal Clinic	773-731-1762	www.clclaw.org/
Statewide	Catholic Charities	312-948-6821	/www.catholiccharities.net/GetHelp/OurServices/LegalServices/CCLA.aspx
Statewide	Coordinated Advice and Referral Program for Legal Services	312-738-9200	www.carpls.org/
Statewide	Legal Aid Society	312-986-4200	www.metrofamily.org/legal-aid/
Statewide	James C. Siebert & Associates	847-253-7500	www.jcslaw.com
Statewide	M. Margaret Bradshaw, P.C.	815-206-2908	http://ssdatty.com/
Statewide	Jenette M. Scwemler	815-245-4665	www.jms-attorney.com
Statewide	Michling, Hofmann, Plaza & Wick	815-338-9600	www.woodstocklawpros.com/
Statewide	Law Offices of Gary R. Waitzman	847-719-1300	www.grweplaw.com/
Statewide	Northern Illinois Center for ElderCARE, P.C.	815-227-1144	www.elderlawrockford.com/
Statewide	Strohschein Law Group	630-377-3241	www.strohscheinlawgroup.com
Statewide	Law Office of Kate Curler	312-952-1077	www.curlerlaw.com
Statewide	Law Offices of Anthony B. Ferraro	847-221-0154	www.abferrarolaw.com
Statewide	Zukowski, Rogers, Flood & McArdle	815-459-2050	www.zrfmlaw.com
Statewide	James Dunneback, P.C.	708-349-0000	http://dunnebacklaw.com/

Exploring options for life insurance can be intimidating and overwhelming. Please see the below resources and connect with an experienced agent who is able to provide you with information about the policies and companies available in your situation.

Location	Name	Contact	Website
Nationwide	HDSA/GINA info	Online	www.hdsa.org/living-with-huntingtons/family-care/living-at-risk/gina-information.html
Nationwide	National Association of Insurance and Financial Advisors	Online	www.naifa.org/consumer/
Nationwide	Buying Life Insurance- CNN Money	Online	http://money.cnn.com/magazines/moneymag/money101/lesson20/
Nationwide	Life insurance to pay for LTC	Online	http://longtermcare.gov/costs-how-to-pay/using-life-insurance-to-pay-for-long-term-care/
Nationwide	Life Happens	Online	www.lifehappens.org/insurance-overview/
Nationwide	Whole life insurance with no medical review	636-266-0172	info@bfgllc.us (United Home Life)
Nationwide	Impaired-risk specialist info	Online	www.insure.com/articles/lifeinsurance/special-risk.html
Nationwide	How to buy life insurance	Online	www.nolo.com/legal-encyclopedia/how-buy-life-insurance-29827.html
Nationwide	10 questions to ask your life insurance agent	Online	www.bankrate.com/finance/insurance/10-questions-life-insurance-agent-1.aspx
Nationwide	MetLife Special Needs Planners	Online	www.metlife.com/individual/planning/special-needs/index.html#overview

Long Term Care insurance can be very pricey and confusing. Please see the below resources and contact your local insurance representative to discuss your options.

Location	Name	Contact	Website
Nationwide	What is LTC	Online	www.hdsa.org/living-with-huntingtons/family-care/asw/lhci.html
Nationwide	MetLife Special Needs Planners	Online	www.metlife.com/individual/planning/special-needs/index.html#overview
Nationwide	Shopper's Guide to LTC insurance	Online	www.ltcfeds.com/epAssets/documents/NAIC_Shoppers_Guide.pdf
Nationwide	Elder Law Answers	Online	www.elderlawanswers.com/long-term-care-insurance
Nationwide	Administration on Aging	Online	www.longtermcare.gov
Nationwide	New & Unexpected Ways to Fund LTC	Online	www.forbes.com/sites/jamiehopkins/2014/04/21/new-and-unexpected-ways-to-fund-long-term-care-expenses/
Nationwide	Genworth Cost Calculator	Online	www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html
Nationwide	John Hancock	Online	www.johnhancock.com/products/long-term-care.html
Nationwide	Mutual of Omaha	Online	www.mutualofomaha.com/long-term-care-insurance/

Below is information about Medicaid in Illinois as well as the Illinois Medicaid Care Coordination/Integrated Care Program.

Location	Name	Contact	Website
Statewide	Online Application for Medicaid	Online	https://abe.illinois.gov/abe/access/
Statewide	ABE Toolkit	Online	www.ageoptions.org/services-and-programs/ABEToolkit.html
Statewide	Care Coordination Expansion Map	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/CCExpansionMap.pdf
Statewide	Care Coordination Rollout Chart	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/CC_rolloutchart.pdf
Statewide	List of Contacts for Medicaid Health Plans	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/ContactListAllMCEs.pdf
Statewide	Illinois Client Enrollment Services	Online	http://enrollhfs.illinois.gov/
Statewide	Care Coordination Webinar	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/063014CCRollOutWebinar.pdf
Statewide	DUAL ELIGIBLES (MEDICARE AND MEDICAID)	Online	www.ageoptions.org/documents/MMAIFAQ_001.pdf
Statewide	Dual Eligible MMAI Program	Online	www.ageoptions.org/documents/1.MMAIWebinar-ADR5114.pdf
Statewide	Dept. of Healthcare and Family Services	877-912-8880	http://enrollhfs.illinois.gov/
Statewide	FAQ on Medicaid Care Coordination	Online	www2.illinois.gov/hfs/SiteCollectionDocuments/063014_webcast_ga.pdf

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 at the moment. The device will call your identified emergency contacts as well as 9-1-1, depending on the particular agreed upon protocol when you purchase a particular system. Please see below to find a system that is right for you and your loved ones.

Location	Name	Contact	Website
Nationwide	Medic Alert Comparison	Online	www.medicalalertcomparison.com/
Nationwide	Medical Alert Reviews- compare companies	Online	http://medical-alert-systems-review.toptenreviews.com/
Nationwide	Choosing a Medic Alert System	Online	http://www.lifestation.com/how_choose.php
Statewide	AP Lifeline- Alyse Cohen Burman and Paula Levy	847-561-9279 847-561-9282	http://affiliates.lifelinesys.com/aplifeline/home/
Nationwide	Medical Guardian	800-668-9200	www.medicalguardian.com/
Nationwide	Medical Alert Systems News	Online	www.medicalalertsnews.com/
Nationwide	Alert1	888-981-9945	http://www.alert-1.com/
Nationwide	Life Alert	800-920-3410	http://www.lifealert.com/
Nationwide	ADT	877-678-6952	http://www.adt.com/medical-alert-systems
Nationwide	E-book- How to Create a Safer Home	Ebook	http://offer.lifelinereferrals.com/create-a-safer-home/

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/using to ensure safety. Call Social Worker for referrals.

Location	Name	Contact	Website
Statewide	Thomas Cellini Foundation (potential donations)	800-277-4288	www.homeopathyplanet.com/TCHF/
Nationwide	Broda Seating	800-668-0637	www.seatingisbelieving.com
Nationwide	In Step Mobility Products, Inc	800-558-7837	www.ustep.com/
Nationwide	Philips Lifeline- medic alert necklace	800-380-3111	www.lifelinesys.com/content/home
Nationwide	HDSA Equipment Board *Please note: HDSA does not participate in any equipment transaction	800-345-4372	Online equipment exchange board facilitates the sharing of durable medical equipment. Go to www.hdsa.org .
Nationwide	Care Foam	877-236-2687	www.carefoam.com/
Nationwide	AbleData- Assistive Technology	800-227-0216	www.abledata.com
Nationwide	Apria Healthcare	800-277-4288	www.apria.com
Nationwide	North Coast Medical	800-821-9319	www.ncmedical.com/
Nationwide	Patterson Medical	800-323-5547	www.pattersonmedical.com/
Nationwide	Gold Violin	877-648-8400	http://goldviolin.blair.com/
Nationwide	Hill-rom	800-445-3730	www.hill-rom.com/usa/

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Location	Name	Contact	Website
Nationwide	Home Sensors for Stove	877-785-9901	www.homesensors.com/
Nationwide	Stove Safety Resources	Online	www.abledata.com/abledata.cfm?pageid=19327&ksectionid=19327&top=160119
Nationwide	Patterson Medical (variety of products)	800-343-9742	www.pattersonmedical.com
Nationwide	Guardian- Strider Walker	800-833-4000	www.rehabmart.com/product/guardian-striderwalker-14973.html
Nationwide	Best Priced Products- Safety Devices (helmets, elbow/knee pads, etc)	800-824-2939	www.best-priced-products.com/
Nationwide	Posey- Safety Products (beds, seating, falls)	800-447-6739	www.posey.com
Nationwide	Gunnel, Inc (chairs)	800-551-0055	www.gunnell-inc.com/
Nationwide	Alimed (cushions, support, eating utensils, padding)	800-225-2610	www.alimed.com/
Nationwide	NOA Medical (Beds and bedding accessories)	800-663-6068	www.noamedical.com/
Statewide	Ramp Now (ramps and lifts)	630-892-7267	www.rampnow.com

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/using to ensure safety. Call Social Worker for referrals.

Location	Name	Contact	Website
Nationwide	Assistech- devices for memory loss/cog impairment (i.e. electronic medication reminders and communication devices)	866-674-3549	www.assistech.com/products/Products-for-Memory-Loss/-Cognitive-Disorders.htm
Nationwide	Dynavox- Speech/communication devices	800-588-4548	www.dynavoxtech.com/default.aspx
Statewide	Illinois Assistive Technology Program- Device Loan Program	217-522-7985	www.iltech.org/deviceloan.html
Nationwide	Independence Lifestyles- safety devices	847-607-1930	www.independencelifestyles.com/
Nationwide	Rest Assured- online communication between working caregiver and loved one at home	847-338-9193	www.restassuredsystem.com/index.htm
Nationwide	Disposable toilet floor mats	Online	www.webstaurantstore.com/search/disposable-toilet-floor-mats.html
Illinois	Donation email list-serv for buying and selling used medical equipment	To be added to the email listing, email Gomma7@aol.com	Email Gomma7@aol.com
Nationwide	Abilities 365	Online	www.abilities365.com/

Medicare benefits can be quite confusing! The below resources are available to assist Medicare beneficiaries to understand their benefits and make the appropriate choices for their own unique situation.

Location	Name	Contact	Website
Nationwide	Medicare	800-772-1213	www.medicare.gov
Statewide	Senior Health Insurance Program	800-548-9034	www.cbrx.il.gov/aging/1news_pubs/publications/SHIPBrochureEnglish.pdf
Statewide	Senior Health Assistance Program	Online	www.state.il.us/aging/1directory/shap.pdf
Nationwide	Health and Disability Advocates	312-223-9600	www.hdadvocates.org/index.asp
Nationwide	Medicare Parts C and D info	Online	www.medicare.gov/Pubs/pdf/11219.pdf
Nationwide	Extra Help Program	800-772-1213	www.ssa.gov/prescriptionhelp/
Nationwide	Medicare Savings Program	800-843-6154	http://tinyurl.com/khc5upv
Nationwide	Medicare Improvement Standards	Online	www.hdsa.org/living-with-huntingtons/advocacy/medicare-improvement-standard.html
Nationwide	Medicare Observation Status	Online	www.medicareadvocacy.org/self-help-packet-for-medicare-observation-status
Nationwide	Medicare Appeals	Online	www.medicare.gov/claims-and-appeals/
Nationwide	Eligibility and Premium Calculator	Online	www.medicare.gov/eligibilitypremiumcalc/
Nationwide	Medicare LINET Program for meds	Online	http://apps.humana.com/marketing/documents.asp?file=1843634

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.

Location	Name	Contact	Website
Nationwide	Difference between the statuses	Online	www.aft.org/pdfs/retirees/dearmarcie071414.pdf
Nationwide	Medicare Self Help Kit	Online	www.medicareadvocacy.org/self-help-packet-for-medicare-observation-status/
Nationwide	Kaiser Foundation FAQ	Online	http://tinyurl.com/mtkza34
Statewide	IL Hospital Association	Online	www.ihatoday.org/uploadDocs/1/observationstayguidelines.pdf

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.

Location	Name	Contact	Website
Nationwide	Needy Meds	Online	www.needy meds.org
Nationwide	Rx Assist	800-668-0637	www.rxassist.org
Nationwide	Partnership for Prescription Assistance	888-477-2669	www.pparx.org/
Nationwide	HD Drugworks	Online	hddrugworks.org
Nationwide	PharmacyChecker.com	Online	Compare Rx prices for medication; see pharmacy ratings and shipping fees: www.pharmacychecker.com
Nationwide	NAMI Rx Asist	Online	www.nami.org/helpline/freemed.htm
Statewide	IL Rx Buying Club for the uninsured	866-215-3463	www.illinoisrxbuyingclub.com/
Nationwide	Senior Health Insurance Program (SHIP)	800-548-9034	Assistance with choosing appropriate Medicare Part D Plan: www.insurance.illinois.gov/SHIP/SHIPBrochure.pdf
Nationwide	Lundbeck, Xenazine USA	888-882-6013	REACH Program: www.xenazineusa.com/MedicationAssistance/Medication-Assistance-REACH.aspx
Nationwide	Caring Voice Coalition	888-267-1440	www.caringvoice.org/
Nationwide	Medicare Interactive-Formulary Tier Exception	Online	www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide_id=1738
Nationwide	Neuro/Psych patient assistance programs	Online	file:///localhost/Users/cori48/Google Drive/Patient Assistance Programs GuideNEW.htm

(Also see Counseling section). In a mental health emergency, please call 911 or take the person to the nearest emergency room. Each county and city/town will vary on services available. Check to see if there is a county mental health department that may provide additional resources in your area. Please call Social Worker for assistance in locating appropriate services in your location.

Location	Name	Contact	Website
Statewide	IL Department of Human Services	800-843-6154	www.dhs.state.il.us/page.aspx?item=29728
Statewide	IL NAMI (National Alliance on Mental Illness)	217-522-1403	www.il.nami.org/
Nationwide	What Families Need to Know about Hospitalization	Booklet	http://tinyurl.com/l6aasxy
Nationwide	Mental Illness and Hospitalization	Online	www.mentalhealthamerica.net/is-hospitalization-necessary
Statewide	Thresholds	773-572-5400	www.thresholds.org/

People with HD often need more calories than most people and thus may need assistance from the following resources such as recipes, home delivered meals, nutritional shakes, etc:

Location	Name	Contact	Website
Nationwide	Nutrition for People with HD	Online	www.renettedavis.com/nutritn.html
Nationwide	Locating a dietician	Online	www.eatright.org/programs/rdnfinder/
Nationwide	HDSA Nutrition and HD	Online	www.hdsa.org/images/content/1/1/11695.pdf
Nationwide	Book for people with swallowing difficulties	Online	www.amazon.com/Easy-Swallow-Chew-Cookbook-Nutritious/dp/0471200743
Nationwide	Ensure Nutritional Shakes (Abbott) Patient Assistance Program	800-222-6885	www.abbottpatientassistancefoundation.org/pdf/Abbott_PAF_Med_Nuts.pdf
Nationwide	Meals on Wheels	Locator by zip code	www.mowaa.org/findameal

Occupational therapy can be very beneficial to help those with HD with maximizing independence and safety with daily activities. Occupational therapists can provide home safety assessments as well. Occupational therapists also can work with caregivers to teach specific techniques with fine motor skills, safety, balance, endurance and overall functioning.

Location	Name	Contact	Website
Nationwide	HDSA Occupational Therapy Guide	Online	www.hdsa.org/images/content/1/1/11697.pdf
Nationwide	Occupational Therapy: We are HDSA	Online	www.hdsa.org/images/content/1/5/15748.pdf
Nationwide	OT Locator via Healthgrades	Online	www.healthgrades.com/
Nationwide	Safety in the Home from HDSA convention	Online	www.hdsa.org/images/content/1/5/15703.pdf

Sometimes caring for a pet while you or a loved one has HD can be stressful and costly. At the same time, pets can also bring much hope and joy to our lives. Please see the below resources for pet care.

Location	Name	Contact	Website
Statewide	Touched by an Animal	773-728-6338	www.touchedbyananimal.org/
Statewide	Anti-cruelty Society	312-644-8338	www.anticruelty.org/
Statewide	Animal Welfare League	773-667-0088	www.animalwelfareleague.com/
Statewide	Banfield Charitable Trust	Online	www.banfieldcharitabletrust.org/#&panel1-1
Statewide	Felines	773-465-4132	www.felinescanines.org/
Statewide	Chicago Community Humane Center	773-764-2242	Please call
Statewide	PAWS	773-521-1408	www.pawschicago.org
Statewide	Tree House Animal Foundation	773-784-5488	www.treehouseanimals.org/
Statewide	Pets-N-Patients	Online	http://petsnpatients.org/

Physical therapy is often underutilized in people with HD, but can be very beneficial in improving quality of life. See below for the benefits of PT as well as types of exercise and interventions that are most useful.

Location	Name	Contact	Website
Nationwide	PT locator- Move Forward	Online	www.apta.org/apta/findapt/index.aspx?navID=10737422525
Nationwide	HDSA Physical Therapy Guide	Online	www.hdsa.org/images/content/1/1/11697.pdf
Nationwide	HDSA Convention Presentation on PT	Online	www.hdsa.org/images/content/2/0/20001/HDSA_PPT%20for%20Physical%20Therapy.pdf
Nationwide	Gait and Balance from HDSA	Online	www.hdsa.org/living-with-huntingtons/family-care/caregivercorner/gnb.html
Nationwide	Early Intervention with PT from the Marker	Online	www.hdsa.org/images/content/1/2/12358.pdf
Nationwide	Gait and Balance Problems from Toward a Cure	Online	www.hdsa.org/images/content/1/2/12759.pdf

Community respite programs are available but limited. Assisted living facilities offer respite services as well for a daily or weekly fee. This is not covered by health insurance. Please contact the resources below for costs/eligibility or call Social Worker for help locating a respite provider.

Location	Name	Contact	Website
Nationwide	Arch Respite Locator	Online	www.archrespite.org/
Statewide	Illinois Respite Coalition	630-529-2871	www.illinoisrespite.org/providers.html
Statewide	IL Dept on Aging Caregiver Program (60yrs+)	800-252-8966	www.state.il.us/aging/1caregivers/program.htm
Statewide	IL Dept of Human Services: Home Services program (under 60 yrs)	800-843-6154	www.dhs.state.il.us/page.aspx?item=29738
Nationwide	Eldercare: Respite locator	800-222-6885	www.eldercare.gov/Eldercare.NET/Public/Resources/Factsheets/Respite_Care.aspx

There are various services from the state for those 60 and over or adults with disabilities. Resources/services include: linking you with local services; case management; respite; food services; information and assistance; socialization; in-home assistance; adult day centers, etc

Location	Name	Contact	Website
Statewide	Area Agency on Aging (AAA)	Online	www.state.il.us/aging/2aaa/aaa-main.htm
Statewide	IL Dept of Human Services: Home Services program (under 60 yrs)- financial eligibility	800-843-6154	www.dhs.state.il.us/page.aspx?item=29738
Chicago	Mayors Office for People with Disabilities	312-746-5773	www.cityofchicago.org/city/en/depts/mopd.html
Statewide	IL Dept. on Aging Community Care Program- financial eligibility	800-252-8966	www.state.il.us/aging/1athome/ccp.htm
Statewide	Catholic Charities	312-217-1697	www.catholiccharities.net/
Statewide	Habilitating Hands medical case management	312-494-5797	www.habilitatinghands.com/
Nationwide	Job Accomodation Network	800-526-7234	www.askjan.org/
Statewide	FITE Center for Independent Living	847-695-5818	www.fitecil.org/Services.asp
Statewide	Centers for Independent Living	217-525-1308	www.incil.org/
Nationwide	Eldercare Consultants- Planning	773-508-1015	www.youreldecareconsultants.com/

Speech and swallowing difficulties can arise due to the motor and cognitive symptoms. Speech-language pathologists can be extremely helpful with these changes and can work with the individual to improve quality of life.

Location	Name	Contact	Website
Nationwide	Locate a Speech Therapist with 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	American Speech Language Hearing Association	Online	www.asha.org/public/speech/disorders/HuntingtonsDisease.htm
Nationwide	Importance of speech therapy/nutrition	Online	http://speech-language-pathology-audiology.advanceweb.com/Article/Huntingtons-Disease.aspx
International	Communication and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/communication-and-hd/
International	Swallowing and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/swallowing-and-hd/
Nationwide	HDSA Nutrition Guide	Online	www.hdsa.org/images/content/1/1/11695.pdf

Support groups are beneficial to help you meet and connect with other individuals who are going through similar life changes and obstacles.

Location	Details	Contact	Location
Central Illinois	2 nd Sunday of even months: 2-4p	Dave or Susie Hodgson 630-386-3928 or spiketdog@softhome.net	St. Joseph Medical Center Busi. Conf. Center Rm 2 2200 E. Washington St. Bloomington, IL
Chicago	4 th Tuesday of even months; 7-8:30p	Sarah Mitchell, Rush Social Worker Sarah_Mitchell@rush.edu or 312 942-6445	Rush Univ. Medical Center Tower Resource Center (Tower, 4 th Floor, Suite 04527) 1620 W. Harrison Street, Chicago
Chicago *At-risk support group	2017 dates: 3/18, 5/13, 7/8, 9/9, 11/11 See http://illinois.hdsa.org/about/support-groups for more details or contact ezivin@hdsa.org	Emily Zivin, Illinois HDSA Chapter Social Worker 630-443-9876 or ezivin@hdsa.org	Northwestern Memorial Hospital See website for room location: http://illinois.hdsa.org/about/support-groups
Geneva	3 or 4 Sunday of odd numbered months 2-3:30p	Joe Wiedemann: 847-505-3933	Delnor Hospital 300 S. Randall Rd. Conference #4 of the 351 Medical Office Bldg. Geneva, IL
Lake County	2 nd Monday of every month 7p	Marilyn and Barry Kahn: 847-975-2403 marilynkahn1@gmail.com	Advocate Condell 801 Milwaukee Ave West Tower Libertyville, IL

Continued on next page

Support groups are beneficial to help you meet and connect with other individuals who are going through similar life changes and obstacles.

Location	Details	Contact	Location
Rockford	2 nd Sunday of every month at 2:pm	Ted Ross: 815-282-0600 tedrosse@comcast.net	OSF St. Anthony Medical Center 5666 E. State St. St. Anthony Room Rockford, IL
South Suburban	2 nd Tues of odd months at 7pm	Maryann Moynihan: 708-955-3080 or shamrock1959@att.net	Thomas Cellini Huntington's Foundation 3019 E. End Ave South Chicago Heights
Munster, IN	2 nd Tues of even months at 7pm	Cindy Rogers: 219-680-6001 or clrogers111@comcast.net	Southside Christian Church 1000 Broadmoor Ave Munster, IN
Telephone Support Group	4 th Sunday of every month at 7pm	Sadie Foster: 815-217-7101	To participate, dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

Transportation resources vary widely between cities and counties. Transportation ranges from public (bus, train, para-transit, dial-a-ride) to private (taxi, wheelchair van, etc). Please call Social Worker for more information.

Location	Name	Contact	Website
Statewide	ADA Paratransit	312-335-1244	www.rtachicago.com/accessibility/ada-paratransit-service-guidelines.html
Statewide	Benefits Access Program (senior and disability free transit ride; license plate discount)	Online	www.state.il.us/aging
Nationwide	American Public Transportation	202-496-4800	www.apta.com/resources/links/unitedstates/Pages/illinoisTransitLinks.aspx
Statewide	Pace Paratransit and Dial-a-Ride	847-364-PACE (7223)	www.pacebus.com/sub/paratransit/default.asp
Statewide	Parking and other Publications and forms for people with disabilities	800-252-8980	www.cyberdriveillinois.com/publications/disabilitypub.html
Statewide	Medicaid only- First Transit	877-725-0569	www.hfs.illinois.gov/rdc/123003_netspap.html
Statewide	Yellow Dot Program- vital information on drivers	217-558-2497	www.yellowdotillinois.org/

Families affected by HD often need adaptive vehicles to properly transport a loved one with HD. Please consult the following resources for adaptive transportation and call Social Worker for further information and resources on transportation and appropriate referrals.

Location	Name	Contact	Website
Nationwide	Access Unlimited- making your vehicle accessible	800-849-2143	www.accessunlimited.com/
Nationwide	Funding Resources for Accessible Vehicles and Adaptive Equipment	866-948-8341	www.nmeda.com/funding-and-rebates/funding-resources-for-accessible-vehicles-adaptive-equipment/
Nationwide	AMS Vans- wheelchair vans	800-775-8267	www.amsvans.com/
Nationwide	IMED Mobility- mobility accessible vehicles	855-543-4951	www.imedmobility.com/
Nationwide	Mobility Works	877-365-0387	www.mobilityworks1.reachlocal.net/
Nationwide	Ride-Away	888-743-3292	www.ride-away.com/index.php
Nationwide	AMS Vans- Financing Wheelchair Vans	800-775-8267	www.amsvans.com/financing-handicap-vans/grants
Nationwide	Finding Accessible Places: AXS Map	Online	www.axsmap.com/

All individuals with HD will eventually lose their ability to drive and this can be a big blow to one's independence. A formal driving evaluation, at an occupational therapy or rehabilitation center may be available and can help both the physician and person with HD by providing objective information about the individual's performance.

Location	Name	Contact	Website
Statewide	Marianjoy (Wheaton, IL)	630-909-6082	www.marianjoy.org/TherapiesandServices/DriverRehabilitation.aspx
Statewide	Rush Day Rehab (Chicago)	847-942-6967	www.rush.edu/rumc/page-1271685207127.html
Statewide	Alexian Brothers (Elk Grove Village, IL)	847-640-3119	www.alexianbrothershealth.org/services/arh/services/specialtyprograms/driver-rehab/
Statewide	Institute for Physical Medicine and Rehabilitation (Peoria, IL)	309-692-8670	www.ipmr.org/driverevaluation.php
Statewide	Provena St. Joseph Medical Center (Joliet, IL)	815-741-7416	//www.provena.org/stjoes/driverrehabilitation
Statewide	Northshore (Evanston, IL)	847-570-1260	www.northshore.org/physical-medicine-rehabilitation/
Statewide	IL Secretary of State-Medical Review Unit	217-782-7246	www.cyberdriveillinois.com/departments/drivers/drivers_license/medical_vision.html
Nationwide	Family Conversations about driving safety	Hartford Publication	www.hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf
Nationwide	Example of a driving contract	Online	www.alz.org/documents_custom/driving_contract.pdf

Sometimes traveling, while enduring symptoms of HD, can be difficult. Please see the below resources for assistance with travel.

Location	Name	Contact	Website
Nationwide	TSA Care	855-787-2227	https://www.tsa.gov/travel/passenger-support
Nationwide	Able to Travel	888-211-3635	www.abletotravel.org/
Nationwide	Flying Wheels Travel	612-381-1622	http://flyingwheelstravel.com/
Nationwide	Disabled Travelers	Online	www.disabledtravelers.com/travel_agents.htm
Nationwide	Rick Steves Travel Tips	Online	www.ricksteves.com/travel-tips/trip-planning/travelers-with-disabilities
Nationwide	Accessible Journeys	Online	http://accessiblejourneys.com/
Nationwide	Emerging Horizons	Online	www.emerginghorizons.com/
Nationwide	Society for Accessible Travel and Hospitality	212-447-7284	www.sath.org/
Nationwide	Mobility International USA	541-343-1284	www.miusa.org/

These virtual caregiving devices can help provide you peace of mind, while enhancing independence as much as possible in the home. They may also help save money or offset the costs of in-home caregiving.

Location	Name	Contact	Website
Nationwide	LivHome Care Monitor	Online	www.livhomecaremonitor.com/
Nationwide	Grand Care Systems	Online	www.grandcare.com/
Nationwide	Care Innovations	Online	www.careinnovations.com/
Nationwide	Be Close	Online	http://beclose.com/
Nationwide	HealthSense	Online	www.healthsense.com/
Nationwide	Ecaring	Online	http://ecaring.com/care-tracker
Nationwide	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	Online	http://caregiver.org/digital-technology-family-caregiver

The below programs can assist with job placement and/or job accommodations

Location	Name	Contact	Website
Nationwide	Job Accommodation Network	800-526-7234	askjan.org/
Statewide	Jewish Vocational Services	855-463-6587	www.jvschicago.org
Statewide	Illinois Assistive Technology Program	800-852-5110	www.itech.org/wipa.html
Statewide	Jane Addams Center for Working Families	773-751-7104	www.jane-addams.org/jarc-programs/center-for-working-families/
Nationwide	National Able Network	855-994-8300	www.nationalable.org
Statewide	Aspire of Illinois	708-547-3550	www.aspireofillinois.org/who-we-help/adult-employment-services.html
DuPage County	Worknet DuPage	630-955-2030	www.worknetdupage.org/job-seekers/advanced-services.php#paep

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

Location	Name	Contact	Website
Nationwide	National Youth Alliance	Mynelly Perez: mperez@hdsa.org	www.hdsa.org/nationalyouthalliance/nya-1/index.html
International	Huntington's Disease Youth Organization	Online	www.en.hdyo.org/
National	Talking with Kids: A Guide for Families	Publication	www.hdsa.org/images/content/1/7/17026/Talking%20with%20Kids%20FG-%20FINAL%20%282%29.pdf
Nationwide	Book: Talking to Kids about HD	Publication	http://www.hdsa.org/images/content/2/0/20292/TWKBrochure%20FINAL%20WEB.pdf
National	HD Articles and Books for Children	Online	www.huntingtondisease.tripod.com/hdlinks/id18.html
Statewide	SIBS- support for those with siblings with special needs	Online	www.sibsnetwork.org/
Nationwide	Juvenile HD Handbook	Online	http://www.hdsa.org/images/content/1/1/11702.pdf
Nationwide	Juvenile HD- Guide for Families	Online	http://www.hdsa.org/images/content/1/4/14767.pdf
Nationwide	JHD and the School Experience	Online	http://www.hdsa.org/images/content/2/4/v2/24235/HDSA-Juv-horiz-13e-part1.pdf and http://www.hdsa.org/images/content/2/4/v2/24236/HDSA-Juv-horiz-13e-part2.pdf

The below organizations help provide wishes to children and adults with terminal illnesses in order to bring peace and improved quality of life to these incredibly brave people.

Location	Name	Contact	Website
Nationwide	Dream Foundation	805-564-2131	www.dreamfoundation.org/ dream-faq
Nationwide	Make a Wish	800-978-WISH	www.wishes.org/

Journaling and legacy writing can be a therapeutic activity for those who are at-risk, gene positive or living with HD as well as family members. 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.

Location	Name	Contact	Website
Nationwide	Legacy Writing	Online	www.legacywriting.com/
Nationwide	Comfort Dying: Books for Legacy Writing	Online	www.comfortdying.com/writing_a_legacy_letter_ethical_will_61662.htm#bookmark2
Nationwide	Legacy Letter Project	Online	www.legacyletterproject.com/legacy.html
Nationwide	Life Legacy Writing	Online	www.lifelegacycoaching.com/legacy_letters.html
Nationwide	Legacy Writing: A Spiritual Practice	Online	www.drweil.com/drw/u/ART03239/Legacy-Writing-A-Spiritual-Practice.html
Nationwide	Emotional Legacy	Online	www.emotionallegacy.com/legacywriting1.htm