

Huntington's Disease Resources

State of Michigan

HDSA Michigan Chapter Social Worker

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Introduction

This document was created to provide information on resources in Michigan 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 Michigan and nation-wide are ever-changing due to budget fluctuations and availability. Please contact the Michigan HDSA chapter social worker, Stephanie Forbes (989) 948-2089 or Sforbes@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 Stephanie!

Acknowledgment

Much gratitude and thanks goes to the Illinois Chapter of HDSA, for providing us this template for the resource guide and also thank you to Aileen K. who helped us put together this guide!

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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, 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) | See website to find your local Area Agency on Aging by service area | https://www.michigan.gov/osa/1,4635,7-234-64081-295815--,00.html |
| Statewide | Michigan Adult Day Services Association | 616-485-5018 | https://www.mimadsa.org/ |
| Nationwide | Elder Care Locator | Online | www.eldercare.gov/Eldercare.NET/Public/Resources/Factsheets/Adult_Day_Care.aspx |
| County/Statewide | County Community Mental Health Agencies (name and resources vary by county) | Online, search by county | https://www.michigan.gov/documents/cmh_8_1_02_37492_7.PDF |

Advanced Directives

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 | Making Choices Michigan | 616-421-4840 | https://makingchoicesmichigan.org/resources/ |
| Statewide | Peace of Mind Registry | 800-482-4881 | https://www.mipeaceofmind.org/Default.aspx |
| Nationwide | Caring Conversations | Online | /www.practicalbioethics.org/download-caring-conversations |
| Nationwide | Advance Care Planning | Online | www.acpdecisions.org/ |
| Statewide | Michigan Department of Health & Human Services | 800-482-4881 | https://www.michigan.gov/mdhhs/0,5885,7-339-71547_2943_70663---,00.html |
| Nationwide | Five Wishes | 888-594-7437 | www.agingwithdignity.org/legal_illinois.php |
| Statewide | Greater Grand Rapids End of Life Coalition | | www.grendoflife.org |
| 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_guid_sersly_ill.authcheckdam.pdf |
| Nationwide | Toolkit for Advanced Healthcare Planning | Online | http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf |

Advanced Directives (Continued)

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 |
|------------|------------------------------------|---------|--|
| 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 |

Aging and Disability Resources

Below are websites that provide information, referral and assistance as well as individual counseling to help people understand their long term care needs and make informed decisions about their services.

| Location | Name | Contact | Website |
|------------|-------------------------------------|--------------|---|
| Nationwide | HDSA- Disability Benefits and HD | Online | https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/ |
| Statewide | MI Office of Services to the Aging | 517-373-8230 | https://www.michigan.gov/osa/1,4635,7-234-64081---,00.html |
| Statewide | Area Agency on Aging Locator | Online | https://www.michigan.gov/osa/1,4635,7-234-64081-295815--,00.html |
| Statewide | MI Disability Resources | Online | http://www.dnmichigan.org/ |
| Nationwide | Administration for Community Living | Online | www.acl.gov/Programs/CDAP/OIP/ADRC/index.aspx#ADRC |

Assistive Devices/Aids for Daily Living

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/ |
| Metro Detroit | Hart Medical Supply | Offices/online | https://hartmedical.org |
| Statewide | Airway Oxygen, Inc. | Offices/online | https://www.airwayoxygeninc.com/ |
| Statewide | J&B Medical Supply | Offices/online | https://www.jandbmedical.com/ |
| Mid-Michigan | Saginaw Medical Supply | Offices/online | www.makelifeaccessible.com/ |
| Statewide | AdvaCare | Offices/online | www.advacaresystems.com/ |
| Nationwide | Liftware- silverware that stabilizes tremor | Online | www.liftlabsdesign.com/ |
| Nationwide | ALS Association | Online | www.alsa.org/als-care/resources/products/ |
| Statewide | Sheldon Medical Supply | Offices/online | https://www.sheldonmedicalsupply.com/ |
| Statewide | Binson's Medical Supply | Offices/online | https://www.binsons.com/ |
| Statewide | Wright and Filippis | Offices/online | http://www.firsttoserve.com/ |

Body and Brain Donation

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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 | U of M - Michigan Brain Bank | North Ingalls Building 400 N. Ingalls St., Room G179 Ann Arbor MI 48109 734-647-7648 | http://www.brainbank.umich.edu/ |
| Nationwide | Gift of Hope | Online | www.giftofhope.org/ |
| Statewide | Gift of Life Michigan | Online | https://www.giftoflifemichigan.org/ |
| Nationwide | Indiana University Brain Bank | Anatomical Education Program Medical Science Building, MS 5035 635 Barnhill Drive Indianapolis, Indiana 46202 | https://medicine.iu.edu/give/gift-types/body-donation/ |

Books on HD and Coping with Illness

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 |

Caregiver Information and Support

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 | 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 | Area Agency on Aging- Caregiver Resources | 800-852-7795 | https://aaa1b.org/caregiver-resources/ |
| Statewide | Michigan Caregiver Resource Guide | Online | https://www.lansingmi.gov/DocumentCenter/View/4370 |
| 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 | Aging Services | Online | https://www.michigan.gov/osa/1,4635,7-234-64081---,00.html |
| Nationwide | E-book: After the Diagnosis | Online | http://www.caregiving.com/store/products/after-the-diagnosis/ |
| Statewide | HDSA Caregivers ONLY Support Group | Joann Stock | http://hdsa.org/osg/ |

Care/Case Managers

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 crises, help with care transitions, solve family disputes, attend doctor appointments, etc.

Most private insurance companies offer medical case management services so check there first if applicable.

| 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 | Michigan Care Management Resource Center | | http://micmrc.org/ |
| Nationwide | Care Coordination | Online | http://nextstepincare.org/uploads/File/Guides/Care_Coordination/Care_Coordination.pdf |
| Metro Detroit | Michigan Case Management | Online or 877-627-6267 | http://www.micmservices.com/ |

Counseling

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. 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.tri-pod.com/internetsupportgroups/ |
| Anywhere | HDSA Telehealth | Online | http://hdsa.org/living-with-hd/hdsa-telehealth/ |
| Statewide | Michigan Community Mental Health Centers | See website to locate a community mental health center near you | https://www.michigan.gov/mdhhs/0,5885,7-339-71550-2941_4868---,00.html |
| Mid-Michigan | Catholic Family Services (open to all, sliding scale) | (989) 797-6638 | http://www.cfssite.org/index.html |
| | | | |

Counselors/Therapists with HD knowledge

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

| Location | Name | Contact | Website/Specialty |
|----------------------|---|---|---|
| Grand Rapids | Kathy Delp, LMSW, CGC | 616-581-3085 | |
| Saginaw | Nan Spence, LPC | (989) 753-8446 | http://www.cfssite.org/index.html |
| Saginaw/Midland | Judith McAtee, LMSW | 1108 Ashman St, Midland, MI 48640 (989)832-9161 | |
| Statewide | Psychology Today online search | Online | https://www.psychologytoday.com/us/groups/grief/michigan |
| Farmington Hills, MI | Andrea Brent, MA, LLP Bryan Peterson, MA, TLLP | 248-793-1501 248-560-7561 | |
| Rochester Hills, MI | Jaime Saal, MA, LPC, NCC | (248) 608-8800 x 231 | The Rochester Center for Behavioral Medicine (rcbm.net) |

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 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 |

Federal Lifeline Programs (telephone/wireless assistance)

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 |

Financial Benefits

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/benefitscalculators.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 | https://www.benefits.gov/benefits/browse-by-state/state/163 |
| Statewide | State Emergency Relief | Online | https://www.michigan.gov/mdhhs/0,5885,7-339-71547_5531---,00.html |
| Statewide | Michigan Medicaid | Online | https://www.michigan.gov/mdhhs/0,5885,7-339-71547_4860---,00.html |
| Statewide | Steve Stilman | Online | https://www.adlerfirm.com |

Financial Benefits (Continued)

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 | 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 |
| 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 |

Financial/Special Needs Planning

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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 |
| Nationwide | Protected Tomorrows | 847-522-8086 | www.protectedtomorrows.com |
| Nationwide | Jan L. Kodner & Associates | 312-922-6688 | www.mysocialsecuritylawyer.com |
| Mid-Michigan | Robert Bourne, PC | 412 Ashman Street, Midland, MI 48640 (989)835-6511 | https://rbournelaw.com/ |
| 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 |
| Michigan | New Possibilities Financial Group | Kurt Davis K_davis@nlgroupmail.com 586-713-3134 | |

Food and Nutrition Assistance

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://www.michigan.gov/mdhhs/0,5885,7-339-71547_5527---,00.html |
| 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 |
| Statewide | MiBridges (FAP) | online | https://newmibridges.michigan.gov/s/isd-landing-page?language=en_US |

Funeral Planning

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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 |
| Nationwide | Funeral Wise | Online | https://www.funeralwise.com/planning/ |
| Nationwide | Planning a Funeral | Online | http://nfda.org/planning-a-funeral.html |
| Statewide | Michigan Care Planning Council | Online | http://www.caremichigan.org/list22_michigan_Funeral_Burial_Pre-Planning_Pre-Need.htm#assistance |
| Nationwide | The Light Beyond | Online | www.thelightbeyond.com/funeral_pre-planning_a_practical_matter.html |

Genetic Counseling Centers

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 | Michigan Association of Genetic Counselors, Inc. | Online list | https://www.magcinc.org/ClinicDirectory.aspx |
| Statewide | University of Michigan Human Genetics | 4909 Buhl Building, 1241 E. Catherine St. Ann Arbor, MI 48109-5618 Phone: (734) 647-3149 dhgcontact@umich.edu | https://medicine.umich.edu/dept/human-genetics/ |
| Statewide | Michigan State University Division of Human Genetics | 1355 Bogue St., Room B123 East Lansing MI 48824 (517)353-2032 | http://www.phd.msu.edu/contact-us2 |
| Statewide | Wayne State University Physicians Group | 1-877-WSU-DOCS (1-877-978-3627) | http://www.wsupgdocs.org/neurology/WayneStateContentPage.aspx?nd=1451 |
| 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&... |

Genetic Discrimination

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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 |

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 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 |
|--------------|---|--|--|
| Statewide | Heartland Hospice | Online | https://www.heartlandhospice.com/locations/ |
| Mid-Michigan | Children's Grief Center, Great Lakes Bay Region | 989-495-9335 admin@childrensgriefglbr.org | https://www.childrensgriefglbr.org/ https://www.facebook.com/childrensgriefcenter/ |
| Statewide | Psychology Today online search | Online | https://www.psychologytoday.com/us/groups/grief/michigan |
| 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

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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 | State Bar of Michigan | Online | https://www.michbar.org/public_resources/probate_guardianship |
| Statewide | Michigan Courts, link for forms needed | Online | http://courts.mi.gov/Administration/SCAO/Forms/Pages/Guardian.aspx |
| 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 | Michigan Guardianship Association | Online | https://michiganguardianship.org/resources/ |

HD Medical Care in Michigan

The health systems 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 the chapter social worker for more education/information.

| Location | Name | Contact | Website |
|----------------------|---|---|---|
| West Bloomfield, MI | Henry Ford Hospital | Dr. Bulica - neurologist Dr. LeWitt- neurologist 248-661-6466 | https://www.henryford.com/physician-directory/p/patel-neepea |
| Ann Arbor, MI | University of Michigan | Dr. Praveen Dayalu- neurologist Dr. Kelvin Chou- neurologist Dr. Roger Albin- neurologist 734-936-9010 | https://www.uofmhealth.org/conditions-treatments/neurosciences |
| Ann Arbor, MI | C.S. Mott Children's Hospital | Dr. Neville - pediatric neurology 734-936-4179 | |
| Royal Oak, MI | Beaumont Hospital | Dr. Adam Kuhlman- neurologist | 855-863-8761 option 3 |
| Farmington Hills, MI | Michigan Institute for Neurological Disorders | Dr. Aaron Ellenbogen - neurologist 248-553-0010 | |
| East Lansing, MI | Michigan State University Neurology | Dr. John Goudreau- neurologist Dr. Christos Sidiropoulos- neurologist 517-353-8122 | |
| Grand Rapids, MI | Spectrum | Dr. Emily Reuther- neurologist Dr. Christopher Kobet- neurologist | 616-267-7104 https://www.spectrumhealth.org/patient-care/neurosciences/movement-disorders |
| Traverse City, MI | | Dr. Cornelius Robens- neurologist 231-642-5701 | |

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 |

HD Specific Resources

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/D500401 |
| 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

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 | Heartland Home Health | Online | https://www.heartlandhomehealth.com/ |
| Nationwide | Care Centrix | Online | www.carecentrix.com/ |
| Statewide | Michigan County Community Mental Health - home help varies by county | Online or call your county office | https://www.michigan.gov/mdhs/0,5885,7-339-71550_2941_4868_4899-178824--,00.html |
| Nationwide | American Academy of Home Care Medicine (house calls) | 410-676-7966 | www.aahcm.org/?Locate A Provider |
| Statewide | Michigan Department of Health and Human Services - Home Help Program | Online or call your local office | https://www.michigan.gov/mdhs/0,5885,7-339-71551_2945_42542_42543_42549_42590---,00.html |

Home Modifications/Accessibility

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 | Ramps.org | Online | http://www.ramps.org/projects-michigan.htm |
| 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 |
| Statewide | Home Advisor - grants for modifications | Online | https://www.homeadvisor.com/r/grants-for-home-modification/ |
| Statewide | Michigan Home Builders' Association | Online | http://www.buildingmichigan.org/ |
| Statewide | Expertise: Home Remodeling for People with Disabilities | Online | https://www.expertise.com/remodeling/home-remodeling-for-disability-and-special-needs |

Hospice and Palliative Care

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.nhpc.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 | The Medical Team Hospice Service- Flint, Livonia, Grand Rapids | 734-452-6021 | http://www.medicalteam.com/Main/Services#HospiceCare |
| 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/ |

Hospice and Palliative Care (Continued)

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 |
|------------|---------------------|--------------|--|
| Statewide | Hospice of Michigan | Online | https://www.hom.org/ |
| Nationwide | Heartland Hospice | 866-231-5695 | www.heartlandhospice.com/ |

Housing: Placement agencies/Locating Facilities in Your Area

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.

| 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 | https://health.usnews.com/best-nursing-homes/area/mi |
| Nationwide | Medicaid and Long Term Care | Book | www.hdsa.org/images/content/2/1/v2/21164/Medicaid-and-LTC-Handbook.pdf |
| Statewide | Michigan Senior Resources | 734-756-5312 | http://mi-seniorresources.com/about-us/ |
| Statewide | | | |
| Statewide | A Place for Mom | 866-333-2174 | A free referral service helping families find nursing homes, assisted living, retirement communities, home care and other living options. www.aplaceformom.com |
| Statewide | Michigan Department of Health and Human Services | Online | https://www.michigan.gov/mdhhs/0,5885,7-339-73971_7122_61243---,00.html Search for available homes by area |
| Statewide | Michigan Healthcare Guide | Online | http://www.mi-hospitals.com/ |

Housing: Assisted and Supportive Living

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.

| Location | Name | Contact | Website |
|------------|--------------------------------|---------|---|
| Statewide | Caring.com | Online | https://www.caring.com/senior-living/assisted-living/michigan |
| Statewide | A Place for Mom | Online | https://www.aplaceformom.com/assisted-living/michigan |
| Statewide | Assisted Living Facilities.org | Online | https://www.assistedlivingfacilities.org/directory/mi/ |
| Nationwide | Care Pathways | Online | www.carepathways.com/ |
| Statewide | Michigan Healthcare Guide | Online | http://www.mi-hospitals.com/ |

Nursing Homes/Facilities and Sites with HD Experience

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 |
| Belding, MI | Metron of Belding | 414 E State Street, Belding, MI 48809 616-794-0460 | www.metronhealth.com |
| St. Clair Shores, MI | St. Mary's Nursing Home | 22601 E 9 Mile Rd, St Clair Shores, MI 48080 586-772-4800 | www.cienahealthcare.com |
| Taylor, MI | Medilodge of Taylor | 23600 Northline Rd, Taylor, MI 48180 734-287-8580 | www.medilodgeoftaylor.com |
| Portage, MI | Medilodge of Portage | 7855 Currier Dr, Portage, MI 49002 269-323-7748 | www.medilodgeofportage.com |
| Adrian, MI | Lynwood Manor | 730 Kimole Lane, Adrian, MI 48221 517-263-6771 | www.lynwoodmanor.com |
| Redford, MI | Nova at Redford (Adult Day Center) | | |
| Bay City, MI | Brookwood Home (AFC Home) | 909 Murphy St., Bay City, MI 48706 989-686-1999 | |

Nursing Homes/Facilities and Sites with HD Experience(Cont.)

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 |
|--|--------------------------------------|--|---|
| Hastings, MI | MagnumCare of Hastings | 240 E North St, Hastings, MI 49058 269-945-9564 | |
| Fenton, MI | Crestmont Nursing Care Center | 111 Trealout Dr., Fenton, MI 48430 810-629-4105 | www.savaseniorcare.com |
| Ludington, MI | Oakview Medical Care Facility | 1001 Diana St., Ludington, MI 49431 | www.oakviewmcf.com |
| Cloverdale, IN | Summerfield Healthcare Nursing Home | 765-795-4260 | http://summerfieldhealthcarecenter.com |
| Specialty Unit in New York dedicated to HD | Terrence Cardinal Cook Health Center | 855-951-CARE | https://www.archcare.org/specialized-care/huntingtons-disease |
| | | | |
| | | | |

Incontinence Resources

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 | The Simon Foundation for Incontinence | Online Search for local diaper bank | https://simonfoundation.org/resources/directory-us-diaper-banks/ |
| Metro Detroit | Detroit Diaper Bank | Online | http://www.detroitareadiaperbank.org/contact-us/ |
| Mid-Michigan | The Diaper Alliance | Online | https://www.thediaperalliance.org/ |
| Mid-Michigan | Mid-Michigan Diaper Bank | Online | https://www.facebook.com/MidMichiganDiaperBank/ |

In-Home Assistance

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 \$20-25 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 | Michigan Department of Health and Human Services - Home Help Program | Online or contact local DHHS office | https://www.michigan.gov/mdhhs/0,5885,7-339-71551_2945_42542_42543_42549_42590---,00.html |
| Nationwide | Right at Home | 877-697-7537 | http://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 | Aging Care.com | Online | https://www.agingcare.com/local/in-home-care |
| Statewide | Care.com | Online | https://www.care.com/home-care |

Insurance Benefits/Healthcare Reform

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

| Location | Name | Contact | Website |
|------------|-----------------------------------|--------------|---|
| 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 | Michigan Legal Help | Online | https://michiganlegalhelp.org/self-help-tools/public-assistance/medical-assistance-ma |
| Statewide | Healthcare.gov | Online | https://localhelp.healthcare.gov/#/ |
| 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 |
| 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 |

Insurance Benefits (Cont.)

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 |
| Nationwide | American Association for Long Term Care Insurance | 818-597-3227 | www.aaltci.org/long-term-care-insurance/ |
| Nationwide | Jan L. Kodner & Associates | 312-922-6688 | www.mysocialsecuritylawyer.com |
| 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 and Forms

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.

| 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 |
| Nationwide | Health and Disability Advocates | 312-223-9600 | www.hdadvocates.org/client_serv/ |
| Mid-Michigan | Robert Bourne | 412 Ashman Street, Midland, MI 48640 989-835-6511 | https://rbournelaw.com/index.aspx? |
| Grand Rapids | Catherine Jacobs | West Michigan Estate Planning Center 616.682.5574 info@cottrelljacobs.com | |
| Grand Rapids | Laurie Murphy Miller Johnson | 616.831.1733 MurphyL@mjsc.com | |

Life Insurance

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

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/ |

Medicaid

Below is information about Medicaid in Michigan

| Location | Name | Contact | Website |
|-----------|---|----------------|---|
| Statewide | Michigan Medicaid Program | | https://www.michigan.gov/mdhhs/0,5885,7-339-71547_4860---.00.html |
| Statewide | MI Bridges- Applying for assistance | 1-855-276-4627 | https://newmibridges.michigan.gov/s/isd-landing-page?language=en_US |
| Statewide | Find community partners or navigators for assistance applying | | https://newmibridges.michigan.gov/s/isd-find-community-partners?language=en_US |
| Statewide | Benefits.gov | | https://www.benefits.gov/benefits/benefit-details/1221 |
| Statewide | | | |

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 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 |
| 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/ |

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

| Location | Name | Contact | Website |
|---|--|--------------|--|
| Illinois (potential donations available for surrounding states) | Thomas Cellini Foundation | 800-277-4288 | www.homeopathyplanet.com/TC/HF/ |
| 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 |
| Statewide | HDSA Michigan | | |
| 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/ |

Medical/Safety Equipment (Continued)

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 | 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/ |

Medical/Safety Equipment (Continued)

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 |
| 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 |
| Nationwide | Abilities 365 | Online | www.abilities365.com/ |

Medicare

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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 |
| 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 |

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.

| 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 |
| Nationwide | Center for Medicare Advocacy | Online | http://www.medicareadvocacy.org/medicare-info/observation-status/ |

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.

| Location | Name | Contact | Website |
|------------|---|--------------|--|
| Nationwide | Needy Meds | Online | www.needymeds.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 |
| Nationwide | HealthWell Foundation | | |
| 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 |

Mental Health/Behavioral Health and Psychiatric Hospitalization

(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 | Michigan Community Mental Health Services | Online or contact local county office | https://www.michigan.gov/mdhhs/0,5885,7-339-71550-2941_4868_4899-178824--,00.html |
| Mid-Michigan | Community Mental Health for Central Michigan | Online | http://www.cmhcm.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 |
| Mid-Michigan and Metro Detroit | Michigan Mental Health Networker | Online | http://www.mhweb.org/ |
| Kalamazoo area | Western Michigan University School of Medicine Psychiatry Clinic | 1717 Shaffer, Suite 010 Kalamazoo 269-337-4363 | med.wmich.edu |

Nutrition/Food

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/rdnf/index/ |
| 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 |
| Mid-Michigan and Metro Detroit | Food Bank of Eastern Michigan | Online | https://www.fbem.org/ |
| Statewide | Nutrition.gov | Online | https://www.nutrition.gov/subject/food-assistance-programs |

Occupational Therapy

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 |
| Mid-Michigan | Covenant Healthcare Physical Medicine and Rehabilitation | Online (989)583-0000 | https://www.covenanthealthcare.com/ch/physicalmedicineandrehab1 |
| | | | |

Pet Care Resources

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 | Michigan Pet Fund Alliance | Online | http://www.michiganpetfund.org/no-kill-equation-toolkit/pet-retention/ |
| Statewide | Basil's Buddies | Online | http://www.basilsbuddies.org/index.php/resourcesa/resources |
| Statewide | Keep Your Pet | Online | http://www.keepyourpet.com/vet-care-assistance/ |
| Statewide | Michigan Humane Society | Online | http://support.michiganhumane.org/site/PageServer?pagename=pet_parenting_help#.WON_ACAkr!U |

Physical Therapy

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 |
| Mid-Michigan | Renue Physical Therapy | 989-450-3341 or online | http://www.renuapt.com/ |
| Mid-Michigan | Covenant Healthcare Physical Medicine and Rehabilitation | (989)583-0000 | https://www.covenanthealthcare.com/ch/physicalmedicineandrehab1 |
| Nationwide | European Huntington's Society | Online | http://eurohuntington.org/active-h |

Respite

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 | Michigan Community Mental Health - services vary by county | Online or local CMH office | https://www.michigan.gov/mdhs/0,5885,7-339-71550_2941_4868_4899-178824--,00.html |
| Nationwide | Eldercare: Respite locator | 800-222-6885 | www.eldercare.gov/Eldercare.NET/Public/Resources/Factsheets/Respite_Care.aspx |

Senior/Disabled Adult Services

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 |
|-------------|--|--------------|---|
| Nationwide | Job Accommodation Network | 800-526-7234 | www.askjan.org/ |
| Nationwide | Eldercare Consultants- Planning | 773-508-1015 | www.youreldecareconsultants.com/ |
| Statewide | Area Agency on Aging (Contact your county) | | http://www.mi-seniors.net/regi onmap/ |
| Statewide | Disability Network Michigan | | http://www.dnmichigan.org/ |
| Kent County | Disability Advocates | | http://www.dakc.us/ |

Speech Therapy

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/ |
| Royal Oak, MI | Speech & Language Pathology-Beaumont Hospital | 248-551-2100 | |
| Mid-Michigan | Covenant Healthcare Physical Medicine and Rehabilitation | (989)583-0000 | https://www.covenanthealthcare.com/ch/speechlanguagecommunicationdisorders |
| Kalamazoo area | Western Michigan University | | |

Support Groups in Michigan

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 |
|--|---|---|---|
| HDSA Online Support Groups | https://www.supportgroupscentral.com/groups_detail_as.cfm?cid=27&CFID=1614129&CFTOKEN=828a1795d7ecc1ab-D696A899-EB39-3E46-F72C431ED5126B08 | 1(800)345-HDSA | http://hdsa.org/osg |
| Royal Oak | 3 rd Sunday at 2PM | Andrea Brent 989-317-5007 or andrea.brent.ma@gmail.com | Beaumont Hospital Administration Building- private dining room 3535 West 13 Mile., Royal Oak, MI 48073 |
| Adrian, MI | 2 nd Thursday monthly | Bill Sprow 517-260-7886 | 130 Sand Creek Hwy Adrian, MI |
| Sterling Heights *Caregiver support group | 2 nd Tuesday monthly at 7:30PM | Joann Stock 586-436-0299 or Jstock7302@wowway.com | 44161 Dylan Sterling Heights, MI |
| Flint | 1 st Monday monthly at 7PM | Jean 810-659-4548 or jeagib@aol.com | Woodhaven Senior Community G-5201 Woodhaven Ct. Flint, MI 48532 |
| Tri-cities | Monthly Sunday | Continued on next page Dave Stickle 989-946-3273 or | Saginaw Fire Department 155 N. G. St. |

Support Groups in Michigan

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 |
|---------------|---|---|--|
| Mt. Pleasant | 2 nd Tuesday monthly at 6PM | Galen Voss: 989-245-5725 or Galenvoss@yahoo.com | Coldwell Bankers 304 East Broadway Mt. Pleasant, MI 48858 |
| Traverse City | Please contact Kathy for upcoming dates | Kathy Delp: 616-581-3085 or Kath6613@aol.com | Munson Community Health Center- room B 550 Munson Ave Traverse City, MI |
| Grand Rapids | 2 nd Thursday monthly at 6:30PM | Kathy Delp: 616-581-3085 or Kath6613@aol.com | Psychotherapy & Consultation Offices, Spaulding Annex Office Complex, 967 Spaulding Ave SE, Suite E, Ada, Michigan 49301 |
| Kalamazoo | Sept-May monthly (group breaks for summer months) Please contact Sara for dates! | Sara Boers: 269-381-7725 or Sara.boers@att.net | First Congregational Church 345 West Michigan Ave Kalamazoo, MI 49007 |
| Lansing | 3 rd Wednesday monthly at 6:30PM | Janet Howes: 517-331-5420 or Sarah George at sgeorge@peckham.org | Peckham, Inc. 3510 Capital City Blvd Lansing, MI 48906 |

Transportation

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 |
|---------------|-------------------------------------|----------------|--|
| Nationwide | American Public Transportation | 202-496-4800 | www.apta.com/resources/links/unitedstates/Pages/illinoisTransitLinks.aspx |
| Statewide | Hour Transportation | 248-569-7500 | http://www.hourtransportation.com |
| Metro Detroit | Give A Lift | (248) 569-5010 | http://givealifttransportation.com/ |
| Metro Detroit | Med Sync Transportation | (734) 646-8846 | https://medsynctransportation.com/ |
| Statewide | SmartBus | | https://www.smartbus.org/ |
| Metro Detroit | GoRide | 248-489-5150 | https://www.beaumont.org/patients-families/goride |
| 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/ |

Transportation (Adaptive)

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 (modifies, rents and sells accessible vehicles) | 877-365-0387 | www.mobilityworks1.reachlocal.net/ |
| Nationwide | Ride-Away | 888-743-3292 | www.ride-away.com/index.php |
| Mid-Michigan | Holt Transportation (disability taxi service) | (989)860-1004 | http://www.holttransport.com |

Transportation: Drivers Evaluation and Rehabilitation Programs

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 | Michigan Driver Evaluation Form | Online | https://www.michigan.gov/documents/O C-88_16727_7.PDF |
| Statewide | Car Fit (assessment events) | Online | https://www.car-fit.org/ |
| Statewide | AAA classes in person and online | Online | https://michigan.aaa.com/safety/mature-driver-training.aspx |
| 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 |

Traveling with a Disability

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/ |

Virtual Caregiving Devices

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 |

Vocational Assistance

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 | Michigan Works Association | 800 285 WORKS (9675) | http://www.michiganworks.org |
| Statewide | Michigan Rehabilitation Services | 800-605-6722 | https://www.michigan.gov/mdhhs/0,5885,7-339-73971_25392_40237_40239-15709--,00.html |
| Nationwide | National Able Network | 855-994-8300 | www.nationalable.org |
| Statewide | Michigan County Community Mental Health | Online or contact local CMH office | https://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_4899-178824--,00.html |
| Metro Detroit | YogaMedics Anne Zemba, Therapist | 248-538-0300 email: info@yogamedics.com | www.yogamedics.com |

Youth

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/nyaa-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 | Michigan NYA Representative | Shelby Lentz shelbylentzmusic@gmail.com | http://www.hdsa.org/about-hdsa/national-youth-alliance/ |
| 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 |
| Michigan | JHD virtual monthly support group | Stephanie: 989-948-2089 | MI Support Groups (hdsa.org) |
| Nationwide | JHD and the School Experience | Online | http://www.hdsa.org/images/content/2/4/v2/24235/HDSA-Juv-horiz-13e-part1.pdf |

Wishes

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/ |
| Statewide | The Rainbow Connection | (248) 601-9474 | https://www.rainbowconnection.org/ |
| Nationwide | Julies List (lists organizations) | Online | http://julieslist.homestead.com/specialwish.html |

Writing Your Legacy

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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 |