HUNTINGTON’S DISEASE RESOURCES

STATE OF ILLINOIS

Prepared by: Cori Robin, LCSW,

Updated by Emily Zivin, LCSW Social Worker

HDSA Illinois Chapter (630) 443-9876

ezivin@hdsa.org

*Updated November 2020*

##  2

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 Emily .

**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.

Table of Contents

**3**

|  |  |
| --- | --- |
| Adult Day Services | 6 |
| Advanced Directives | 7-8 |
| Aging and Disability Resource Networks (ADRN) | 9 |
| Assistive Devices/Aids for Daily Living | 10 |
| Body and Brain Donation | 11 |
| Books on HD | 12 |
| Caregiver Information and Support | 13 |
| Care Managers | 14 |
| Counseling | 15-20 |
| Family Planning | 21 |
| Federal Lifeline Programs (Wireless/phone assistance) | 22 |
| Financial Benefits Programs | 23-24 |
| Financial Special Needs Planning | 25 |
| Food and Nutrition Assistance | 26 |
| Funeral Planning | 27 |
| Genetic Counseling in Illinois | 28 |
| Genetic Discrimination | 29 |
| Grief and Loss | 30 |
| Guardianship | 31 |
| HD Specific Medical Care in Illinois | 32 |

Table of Contents (Continued)

**4**

|  |  |
| --- | --- |
| HD Research | 33 |
| HD Specific Resources | 34 |
| Home Health | 35 |
| Home Modifications/Accessibility | 36 |
| Hospice and Palliative Care | 37-38 |
| Housing Placements/Agencies | 39 |
| Housing: Skilled Nursing Facilities/Nursing Homes | 40 |
| Nursing Homes/Skilled Nursing Facilities with HD Experience | 41-45 |
| Incontinence Resources | 46 |
| In-Home Assistance | 47 |
| Insurance Benefits/Healthcare Reform | 48-49 |
| Legal Assistance | 50-51 |
| Life Insurance | 52 |
| Long Term Care Insurance | 53 |
| Medicaid | 54 |
| Medical Alert Systems | 55 |
| Medical/Safety Equipment | 56-58 |
| Medicare | 59 |

Table of Contents (Continued)

**5**

|  |  |
| --- | --- |
| Medicare Observation Status | 60 |
| Medication Assistance | 61 |
| Mental/Behavioral Health and Psychiatric Hospitalization | 62 |
| Nutrition/Food | 63 |
| Occupational Therapy | 64 |
| Pet Care Resources | 65 |
| Physical Therapy | 66 |
| Respite | 67 |
| Senior/Disabled Adult Services | 68 |
| Speech Therapy | 79 |
| Support Groups in Illinois | 70-71 |
| Transportation | 72 |
| Transportation (Adaptive) | 73 |
| Driver’s Evaluation and Rehab Programs | 74 |
| Travelling with a Disability | 75 |
| Virtual Caregiving Devices | 76 |
| Vocational Assistance | 77 |
| Youth | 78 |
| Wishes | 79 |
| Writing Your Legacy | 80 |

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/](http://www.state.il.us/aging/)1directory/adult\_day.pdf |
| Statewide | Illinois Adult Day Services Association | 773-202-4130 | [www.iadsa.com](http://www.iadsa.com/) |
| Nationwide | Elder Care Locator | Online | https://eldercare.acl.gov/Public/Index.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 | https://[www.isms.org/Resources/](http://www.isms.org/Resources/)For\_Physicians/ Advance\_Directives\_Resources/ |
| Statewide | New POLST- Physician Orders for Life- sustaining Treatment | 855-705-7845 | /[www.polst.org/](http://www.polst.org/) |
| Nationwide | Caring Conversations | Online | https://[www.practicalbioethics.org/](http://www.practicalbioethics.org/)download-caring-conversations |
| Nationwide | Advance Care Planning | Online | [www.acpdecisions.org/](http://www.acpdecisions.org/) |
| Statewide | Illinois Department of Public Health | 217-782-4977 | [www.idph.state.il.us/public/books/advin.htm](http://www.idph.state.il.us/public/books/advin.htm) |
| Nationwide | Five Wishes | 888-594-7437 | https://fivewishes.org |
| Statewide | Chicago End of Life Care Coalition | 773-296-7247 | https://[www.lifemattersmedia.org/tag/](http://www.lifemattersmedia.org/tag/)chicago-end-of-life-care-coalition/ |
| Nationwide | Discussion starters | Online | [www.mydirectives.com/en/Discussion-Guide](http://www.mydirectives.com/en/Discussion-Guide) |
| Nationwide | MedicAlert Foundation | 888-633-4298 | [www.medicalert.org/services/adults](http://www.medicalert.org/services/adults) |
| Nationwide | Compassion and Choices | 800-247-7421 | [www.compassionandchoices.org/](http://www.compassionandchoices.org/) |
| Nationwide | Toolkit for Advanced Healthcare Planning | Online | https://[www.americanbar.org/groups/](http://www.americanbar.org/groups/)law\_aging/resources/ health\_care\_decision\_making/ consumer\_s\_toolkit\_for\_health\_care\_advanc e\_planning/ |

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/](http://www.caringinfo.org/files/public/brochures/)End-of-Life\_Decisions.pdf |
| Nationwide | Conversations Before the Crisis | Online | [www.caringinfo.org/files/public/brochures/](http://www.caringinfo.org/files/public/brochures/)Conversations\_booklet.pdf |
| Nationwide | Artificial Nutrition and Hydration | Online | [www.caringinfo.org/files/public/brochures/](http://www.caringinfo.org/files/public/brochures/)ArtificialNutritionAndHydration.pdf |
| Nationwide | Managing Someone Else’s Money | Online | [www.consumerfinance.gov/blog/managing-](http://www.consumerfinance.gov/blog/managing-)someone-elses-money/ |
| Nationwide | HDSA Guide on Advanced Directives | Online | <http://hdsa.org/wp-content/uploads/>2015/03/HDSA\_Family-Guide-Advance- Directives-for-HD.pdf |

ADRNs 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 | https://eldercare.acl.gov/public/about/aging\_network/adrc.aspx |
| Nationwide | Administration for Community Living | Online | https://acl.gov |

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 | https://abledata.acl.gov |
| Nationwide | Liftware- silverware that stabilizes tremor | Online | [www.liftlabsdesign.com/](http://www.liftlabsdesign.com/) |
| Nationwide | ALS Association | Online | [www.alsa.org/als-care/resources/products/](http://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 | https://hbtrc.mclean.harvard.edu/ donate/ |
| Statewide | Rush University Medical Center\* Only accepts brains from those who are or have been Rush patients | 312-563-2900Or call brain bank clinic coordinator, Tracy Waliczek at 312-563-2848 | https://[www.rushu.rush.edu/](http://www.rushu.rush.edu/)rush-medical-college/ departments/cell-and- molecular-medicine/body- donation |
| Nationwide | Gift of Hope | Online | [www.giftofhope.org/](http://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 | https://hdsa.org/shop/publications/ |
| 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 | Family Care Navigator: State-by-State List from Family Caregiver Alliance | Online | [www.caregiver.org/caregiver/jsp/](http://www.caregiver.org/caregiver/jsp/)fcn\_content\_node.jsp?nodeid=2083 |
| Nationwide | Website for Rare Disease Caregivers | Online | [www.rarecaregivers.org/](http://www.rarecaregivers.org/) |
| Statewide | Illinois Family Caregiver Support Program | 800-252-8966 | [www.state.il.us/aging/1caregivers/](http://www.state.il.us/aging/1caregivers/)program.htm#eligible |
| Nationwide | Caring From a Distance | Online | [www.cfad.org/](http://www.cfad.org/) |
| Nationwide | Lotsa Helping Hands | Online | https://hdsa.lotsahelpinghands.com/info/ |
| Nationwide | HDSA Support Groups | Online | https://hdsa.org/find-help/community-social-support/hdsa-support-groups/ |
| Statewide | Illinois HDSA Chapter Support Groups | Online during Covid | https://illinois.hdsa.org/about/support-groups |
| Nationwide | HD Lighthouse | Online | [www.hdlf.org](http://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/ |

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](http://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/](http://www.livhome.com/) |
| Cook and Collar Counties | Creative Care Management | 847-869-5118 | [www.creativecaremanagement.com/](http://www.creativecaremanagement.com/) |
| Statewide | Lifecare Innovations | 630-953-2154 | [www.lcius.com/](http://www.lcius.com/) |
| Statewide | SeniorBridge | 866-506-1212 | [www.seniorbridge.com/](http://www.seniorbridge.com/) |
| Statewide | Sanders and Warren | 630-858-6466 | [www.sandersandwarren.com/](http://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](http://www.psychologytoday.com/)\*Navigate your preferred choices |
| Anywhere | HDSA Free Virtual Counseling (8 free sessions a year) | Online | https://hdsa.org/find-help/community-social-support/ hdsa-telehealth/ |
| Statewide | Illinois Community Mental Health Centers | 800-843-6154 to locate a community mental heath center near you | [www.dhs.state.il.us/page.aspx?](http://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 acceptsMedicare |
| Bloomington, IL | Samantha Wheeler, PhD | 309-717-0819 x106swheeler@psychol ogyspecialists.com | [www.psychologyspecialists.com/](http://www.psychologyspecialists.com/)Chronic illness |
| Bloomington, IL | Trey Polesky, LCSW | 773-819-5428 | Sees patients with chronic and progressivehealth issues |
| Bourbonnais, IL | Life in Balance | 866-787-4443 | https://[www.lifeinbalanceservices.com](http://www.lifeinbalanceservices.com/) |
| Champaign, IL | Carla Cravens, LCSW | 217-398-9066 | Chronic illness; dementia; grief |
| Champaign, IL | Suzanne Martinez, LMFT | 217-398-8100 | [www.cutherapist.com/](http://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@urbanbal ance.com | https://thrivingpath.com |
| Chicago, IL | Lynne Kavin, LCSW | 773-336-2579 | Specializes in chro[nic illness www.lynnekavin.com/](http://www.lynnekavin.com/) |
| Chicago, IL | Chicago Center for Family Health | 312-372-4745 | [www.ccfhchicago.org](http://www.ccfhchicago.org/) |
| Evanston, IL | Sherrie All, PhD | 855-COGWELL | [www.cogwellness.com](http://www.cogwellness.com/) |
| Chicago, IL | Sara Miller, LCPC | 872-216-0384 | [www.abilityarts.com](http://www.abilityarts.com/) |
| Chicago, IL | Liza Guequierre, PsyD | 312-380-9581 | [www.alliancecbt.com](http://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](http://www.marykelleherlmft.com/) |
| Crystal Lake, Gurnee, Buffalo Grove & Hoffman | Arbor Counseling Center | 847-913-0393 | /[www.arborcounselingcenter.com/](http://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 |

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website/Specialty** |
| Elgin, IL | Tracy Wright, LCPC | 224-856-5988 | https://[www.psychologytoday.com/us/](http://www.psychologytoday.com/us/)therapists/renewed-hope-counseling- services-elgin-il/117220 |
| Evanston/Northbrook, IL | Marcy LaKind, LCSW | 847-840-8126 | [http://www.marcyltherapy.com](http://www.marcyltherapy.com/) |
| Evanston, IL | Mary Senn, LCSW | 847-328-4074 | [www.marysenn.com/](http://www.marysenn.com/)Flexible fee option; works with caregivers and those with chronic illness |
| Geneva, IL | Priscilla Brinkman, LCSW | 630-471-2117 | [www.pbrinkman.com](http://www.pbrinkman.com/) Flexible fee option;grief/loss; children, adults, families |
| Glen Carbon, IL | Jean McGurk O’Brien, LPC | 618-980-2358 | https://[www.newleafcounsel.com/about](http://www.newleafcounsel.com/about) |
| Grayslake, IL | Therapy 4 Kids | 773-315-3114 | [www.therapy4kidz.biz/](http://www.therapy4kidz.biz/) |
| Hinsdale, IL | Nancee Biank, LCSW | 630-655-9864 | Children and family experiencing familyillness [www.nanceesplace.com](http://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/](http://www.findingbalanceltd.com/) |
| Lemont, IL | Susan Jacobowski, LCSW | 630-257-5757 | [www.waterfallcounseling.com/](http://www.waterfallcounseling.com/) |
| Libertyville, IL | Mindy Foreman |  | https://libertyvillecg.com/meet-our-team/ |
| Lincoln, IL | Jennifer Imig Huffman, PhD | 262-671-1494 | Neuropsychologist specializing inmovement disorders |

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website/Specialty** |
| Mendota and Rochelle, IL | Changes Counseling, LLC | 815-562-2088 | [www.changescounselingllc.com/](http://www.changescounselingllc.com/) |
| Naperville, IL | Nowell & Associates | 630-428-2344 | [www.nowellandassociates.org/](http://www.nowellandassociates.org/) |
| Oak Forest, IL | Anne Morrill-Ploum/Genesis | 708-535-7320 x13 | Children, young adults and families[www.genesistherapy.org](http://www.genesistherapy.org/) |
| Oak Park, Oak Brook and Chicago | Smart Love Family Services | 708-660-4300 | [www.smartlovefamily.org/](http://www.smartlovefamily.org/) For parentsand children; Parent coaching/counseling |
| Oak Lawn, IL | Janhavi Desai, PhD | 773-295-2893 | [www.southwestcaregroup.com/](http://www.southwestcaregroup.com/) |
| Oak Lawn, IL and LaGrange, IL | Ankur Varma, M.A. | 708-423-3361 x36 | [www.genesistherapy.org](http://www.genesistherapy.org/) Sliding scale |
| Olympia Fields, IL | Mary Ann Riksheim | 708-748-8309 | [www.marlcsw.com/](http://www.marlcsw.com/) |
| Quincy, IL | Janet Hay | 217-653-5454 | Grief counseling |
| Quincy, IL | Jerry Walker, LCPC | 217-228-6194 | [www.jerrywalkertherapyservices.com/](http://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/](http://www.prapsych.com/) Specializes in chronicillness and its effects on family |
| Schaumburg, IL | Jennifer Budruweit, LPC | 630-448-0658 | [www.lbcounseling.com/](http://www.lbcounseling.com/) |
| Skokie, IL | Rachel Dubrow, LCSW | 847-313-8074 | [www.racheldubrowlcsw.com/](http://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#](http://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/](http://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 |
| Troy, Il | Eve Kuckuck, ATR, LCPC | 618-659-8787 | Kids/teens- grief and loss; https://[www.psychologytoday.com/us/therapists/](http://www.psychologytoday.com/us/therapists/) eve-kuckuck-troy-il/130550 |
| 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 |
| Willowbrook, IL | Many Providers | 630-269-2886 | https://lifecounselinginstitute.com |
| 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/](http://www.inhomecounselingforseniors.com/) |
| Cook county In-home counseling and Chicago | John Kalmus, LCSW | 630-733-1796 | Please call. Does in-home visits in CookCounty. |

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.co](http://www.reproductivegenetics.co/)m/ |
| Nationwide | Stanford HOPES Family Planning Resources | Online | [www.stanford.edu/group/](http://www.stanford.edu/group/)hopes/cgi-bin/wordpress/ 2011/07/family-planning/ |
| Nationwide | HD Free with PGD | Online | [www.hdfreewithpgd.com/](http://www.hdfreewithpgd.com/) |
| Nationwide | Protected Tomorrows- Future Care planning re: education, residential, financial, legal, healthcare, benefits, employment and recreation | 847-522-8086 | [www.protectedtomorrows.co](http://www.protectedtomorrows.co/)m/ |
| Cleveland and Houston | Help Cure HD: Grants for PGD | Online | https://helpcurehd.org |
| 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](http://www.safelinkwireless.com/) |
| Nationwide | Lifeline phone assistance | Online | https://[www.fcc.gov/lifeline-consumers](http://www.fcc.gov/lifeline-consumers) |

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/](http://www.benefitscheckup.org/) |
| Nationwide | PowerWallet Money Management | Online | [www.powerwallet.com/](http://www.powerwallet.com/) |
| Nationwide | Social Security Disability | 800-772-1213 | [www.ssa.gov/applyfordisability/](http://www.ssa.gov/applyfordisability/) |
| Nationwide | Calculator to Check Your Estimated Social Security Benefits | Online | [www.socialsecurity.gov/planners/](http://www.socialsecurity.gov/planners/)benefitcalculators.htm |
| Statewide | CEDA- emergency help for vision, dental, healthcare | 312-782-2332 | https://[www.cedaorg.net](http://www.cedaorg.net/) |
| Nationwide | HDSA SSDI Assistance | Online | https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and- hd-2/ |
| 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 | 312-860-7417 | [www.yourbenefitsadvocate.com/](http://www.yourbenefitsadvocate.com/) |
| Statewide | Envision Benefits- Lori Martin | 708-243-5768 | [www.envision-benefits.com/](http://www.envision-benefits.com/) |
| Nationwide | Allsup-SSDI representation | 800-854-1418 | [www.allsup.com/](http://www.allsup.com/) |
| Nationwide | Protected Tomorrows | 847-522-8086 | [www.protectedtomorrows.com](http://www.protectedtomorrows.com/) |
| Nationwide | Jan L. Kodner & Associates |  | [www.mysocialsecuritylawyer.com](http://www.mysocialsecuritylawyer.com/) |
| Statewide | Common Medicaid Mistakes | Online | <http://tinyurl.com/9we2eqc> |
| Statewide | Wells Fargo- Trust and Fiduciary Specialist- Allison Getz | 1-877-646-8560 | [www.wellsfargo.com/investing/](http://www.wellsfargo.com/investing/)investmentservices/trust/ |
| Nationwide | American Association of Daily Money Managers | 814-355-2452 | [www.aadmm.com/](http://www.aadmm.com/) |
| 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 |  | https://[www.metlife.com/blog/money/](http://www.metlife.com/blog/money/)special-needs-families/ |
| Statewide | Envision Benefits- Lori Martin | 708-243-5768 | [www.envision-benefits.com/](http://www.envision-benefits.com/) |
| Nationwide | Protected Tomorrows | 847-522-8086 | [www.protectedtomorrows.com](http://www.protectedtomorrows.com/) |
| Nationwide | American Association of Daily Money Managers | 877-326-5991 | [www.aadmm.com/](http://www.aadmm.com/) |

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.dhs.state.il.us/page.aspx?](http://www.dhs.state.il.us/page.aspx)item=33698 |
| 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 | https://[www.dhs.state.il.us/page.aspx?](http://www.dhs.state.il.us/page.aspx)item=30366 |
| Chicago only | Commodity Supplemental Food Program (CSFP) | 217-524-3354 | https://govappsqa.illinois.gov/gata/csfa/Program.aspx?csfa=667 |
| Statewide | Feeding Illinois | Online | [www.feedingillinois.org/](http://www.feedingillinois.org/) |
| Statewide | Food Pantries in Illinois | Online | [www.foodpantries.org/st/illinois](http://www.foodpantries.org/st/illinois) |
| Statewide | Solve Hunger Today | Online | https://solvehungertoday.org |
| Statewide | Illinois Food Connections | Online | [www.dhs.state.il.us/page.aspx?](http://www.dhs.state.il.us/page.aspx)item=31245 |
| Statewide | Chicago Greater Food Depository | 773-247-3663 | https://[www.chicagosfoodbank.org](http://www.chicagosfoodbank.org/) |

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/](http://www.mywayforward.com/) |
| Nationwide | Death for Beginnings- Planning Guide | Online | [http://deathforbeginners.com](http://deathforbeginners.com/) |
| Statewide | Pre-need Funeral and Burial Guide | Online | https://illinoiscomptroller.gov/comptroller/assets/File/ NEW%20Pre-Need%20Funeral%20Booklet-format\_Layout%201.pdf |
| Nationwide | Planning a Funeral | Online | <http://nfda.org/planning-a->funeral.html |
| Statewide | Illinois Funeral Directors Association | Online | https://[www.ifda.org](http://www.ifda.org/) |
| Statewide | Pre-Planning FAQ | Online | https://[www.ifda.org/page/](http://www.ifda.org/page/)FuneralPreplanning |
| Nationwide | The Light Beyond | Online | [www.thelightbeyond.com/](http://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, IL312- 942-5003 | https://[www.rush.edu/services/](http://www.rush.edu/services/)conditions/huntingtons-disease |
| Statewide | Northwestern Medicine HDSA Center of Excellence | 675 North St. Claire, Chicago,IL312 695-7950 | https://[www.nm.org/conditions-and-](http://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, IL847-723-7705 | https://[www.advocatehealth.com/](http://www.advocatehealth.com/)health-services/cancer-institute/ cancers-we-treat/breast-cancer/ genetic-testing-and-counseling |
| Statewide | Central DuPage Hospital Movement Disorders Center | Dr. Martha McGraw 630-933-4056 | https://[www.nm.org/locations/central-](http://www.nm.org/locations/central-) dupage-hospital-movement-disorders- center |
| Nationwide | GINA (Genetic Non Discrimination Act): | Online | [www.genome.gov/24519851](http://www.genome.gov/24519851) |
| Nationwide | HDSA GINA Toolkit | Online | [www.hdsa.org/gina](http://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&JavaScri pt=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 | https://[www.eeoc.gov/genetic-](http://www.eeoc.gov/genetic-)information-discrimination |
| Nationwide | Gina Help | Online | [www.ginahelp.org/](http://www.ginahelp.org/) |
| Nationwide | HD and GINA | Online | https://hdsa.org/product/genetic-testing-for-huntingtons- disease-its-relevance-and- implications/ |
| Nationwide | Coalition for Genetic Fairness | Online | [www.geneticfairness.org/](http://www.geneticfairness.org/)GINAPublication111008.pdf |

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 | Rainbow Hospice Grief and Loss Center (many types of grief groups and in several languages) | 847-692-8884 | https://rainbowhospice.org |
| Statewide | Center for Grief Recovery | 773-274-4600 | [www.griefcounselor.org](http://www.griefcounselor.org/) |
| Statewide | Youth Grief Groups | Online | [www.dougy.org/grief-support-](http://www.dougy.org/grief-support-)programs/ |
| Statewide | Hello Grief (support for teens) | Online | https://teenlineonline.org/yyp/hello-grief/ |
| Statewide | Good Mourning Children’s Grief Program | Online |  https://rainbowhospice.org/grief-loss/support-for-children-and- families/good-mourning/ |
| Statewide | LOSS: Loving Outreach to Survivors of Suicide | Online | [www.catholiccharities.net/loss](http://www.catholiccharities.net/loss) |
| Nationwide | Open to Hope | Online Support Forum | [www.opentohope.com/](http://www.opentohope.com/) |
| Nationwide | No Wrong or Right Way to Grieve | Online | [www.caringinfo.org/files/public/](http://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](http://www.guardianship.org/) |
| Nationwide | ABA Commission on Law and Aging | Online | https://[www.americanbar.org/](http://www.americanbar.org/)groups/law\_aging/resources/ guardianship\_law\_practice/ |
| Nationwide | Center for Elders and the Courts | Online | [http://eldersandcourts.org](http://eldersandcourts.org/) |
| Nationwide | National Academy of Elder Law Attorneys | Online | [www.naela.org/Public/](http://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. Deborah Hall - Movement Disorder Specialist312-563-2030Email: Movement\_disorder@rush.edu | https://[www.rush.edu/](http://www.rush.edu/) services/conditions/ huntingtons-disease |
| Chicago, IL | HDSA Center of Excellence and Northwestern Medicine | Dr. Danny Bega - Movement Disorder Specialist 312 695-7950Email: hd@nm.org | https://[www.nm.org/](http://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- Internal Medicine 815-972-1000 | http:// rockford.medicine.uic.edu/ departments/academic- departments/biomedical- sciences/directory/name/ mitchell-king/ |
| Peoria, IL | Illinois Neurological Institute | Dr. Luis E. Zayas-Rodgruguez - Movement Specialist309-624-4000 | <http://m.ini.org/services/> movement-disorders-center/ |
| Winfield, IL | Northwestern Medicine: Central DuPage Hospital Movement Disorders Center | Dr. Martha McGraw, 630-933-4056 | https://[www.nm.org/](http://www.nm.org/) locations/central-dupage- hospital-movement-disorders- center |

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](http://www.hdtrialfinder.org/) |
| European Huntington’s Disease Network | [www.euro-hd.net](http://www.euro-hd.net/) |
| CHDI Foundation, Inc | [www.chdi-inc.org](http://www.chdi-inc.org/) |
| HD Buzz- HD research in real person’s language! | [www.Hdbuzz.net](http://www.Hdbuzz.net/) |
| Huntington Study Group | [www.huntington-study-group.org](http://www.huntington-study-group.org/) |
| HD Drug Works | [www.Hddrugworks.org](http://www.Hddrugworks.org/) |
| HD: Hope Through Research: National Institute of Neurological Disorders and Strokes | [www.ninds.nih.gov/disorders/huntington/detail\_huntington.htm](http://www.ninds.nih.gov/disorders/huntington/detail_huntington.htm) |
| Stanford Hopes | [www.stanford.edu/group/hopes/cgi-bin/wordpress/](http://www.stanford.edu/group/hopes/cgi-bin/wordpress/) |

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](http://www.hdsa.org/) |
| HDSA publications | Online | [www.hdsa.org/archive](http://www.hdsa.org/archive) |
| Mayo Clinic Huntington’s Information | On-line | [www.mayoclinic.com/health/huntingtons-disease/](http://www.mayoclinic.com/health/huntingtons-disease/) DS00401 |
| The HD Advocate | On-line | [http://www.thehdadvocate.org](http://www.thehdadvocate.org/) |
| HD Lighthouse | On-line | [www.hdlighthouse.org](http://www.hdlighthouse.org/) |
| Huntington’s Outreach Project for Education at Stanford (HOPES) | On-line | https://hopes.stanford.edu |
| HD Centers of Excellence | On-line | https://hdsa.org/find-help/clinical-care-services/hdsa- centers-of-excellence/ |
| HSG: Huntington Study Group | On-line | [www.huntington-study-group.org/](http://www.huntington-study-group.org/) |
| HD Buzz | On-line | [www.hdbuzz.net/](http://www.hdbuzz.net/) |
| HD Drug Works | On-line | [www.hddrugworks.org/](http://www.hddrugworks.org/) |
| HDYO | On-line | https://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 | Online202-547-7424 | https://[www.nahc.org](http://www.nahc.org/) |
| Nationwide | Home Health Compare: U.S. Dept of Health and Human Services, Centers for Medicare and Medicaid Services | 800-633-4227 | [www.medicare.gov/](http://www.medicare.gov/)homehealthcompare/search.aspx |
| Statewide | CJE Home Safety Assessment | 773-508-1000 | https://[www.cje.net/node/204](http://www.cje.net/node/204) |
| Nationwide | Care Centrix | Online | [www.carecentrix.com/](http://www.carecentrix.com/) |
| Statewide | Memory Care Corp- Speech Therapy and Occupational Therapy | 630-800-2444 | [www.memorycarecorp.com/](http://www.memorycarecorp.com/)index.html |
| Nationwide | American Academy of Home Care Medicine (house calls) | 410-676-7966 | [www.aahcm.org/?](http://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-](http://www.ilsremodel.com/accessibility-)services/ |
| Nationwide | Extended Home Living Services | 847-999-7909 | [www.ehls.com/](http://www.ehls.com/) |
| Statewide | Leslie M. Stern Design | 773-248-2049 | https://lesliemsterndesign.com/special-needs.php |
| Illinois | List of Home Modification Funding Sources | Online | https://[www.dhs.state.il.us/](http://www.dhs.state.il.us/)page.aspx?item=32042 |
| Nationwide | Ramp Up | 708-444-8460 x231 | https://ucpseguin.org/technology\_services/ramp\_up.html |
| Chicago | HomeMod Program through Mayor’s Office for People with Disabilities |  | [www.cityofchicago.org/city/en/](http://www.cityofchicago.org/city/en/)depts/mopd/provdrs/hous/svcs/ accessible\_home\_modificationprog ram-ages0-5911.html |
| Illinois and Wisconsin | Bridgeway Independent Living Designs | 262-671-2032 | [www.bildnow.com/](http://www.bildnow.com/) |
| Illinois and Indiana | Access | 630-423-5030 | [www.accesselevator.net/](http://www.accesselevator.net/) |
| Nationwide | Abilities 365 | Online | https://ability360.org |

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](http://www.nhpco.org/) |
| Nationwide | Hospice Directory | Online | [http://www.nationalhospicelocator.com](http://www.nationalhospicelocator.com/) |
| Nationwide | American Hospice Foundation | Online | [www.americanhospice.org/](http://www.americanhospice.org/) |
| Nationwide | American Academy of Hospice and Palliative Medicine | Online | [www.aahpm.org/](http://www.aahpm.org/) |
| Nationwide | Questions to Ask Hospice Providers | Online | [www.caregiverslibrary.org/Portals/0/](http://www.caregiverslibrary.org/Portals/0/)ChecklistsandForms\_QuestionsAboutHospic eCare.pdf |
| Nationwide | Ever Plans | Online | [www.everplans.com/](http://www.everplans.com/) |
| Nationwide | Get Palliative Care | Online | [www.getpalliativecare.org/](http://www.getpalliativecare.org/) |
| Statewide | Illinois Hospice and Palliative Care Organization | Online | [www.il-hpco.org/](http://www.il-hpco.org/) |
| Nationwide | Caring Connections | Online | [www.caringinfo.org/](http://www.caringinfo.org/) |
| Nationwide | Compassion and Choices | Online | [www.compassionandchoices.org/](http://www.compassionandchoices.org/) |
| Nationwide | Aging with Dignity | Online | [www.agingwithdignity.org/](http://www.agingwithdignity.org/) |
| Nationwide | Center to Advance Palliative Care | Online | [www.capc.org/](http://www.capc.org/) |

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 | Journey Care | Online | [www.carecenter.org/](http://www.carecenter.org/) |
| Statewide | Rainbow Hospice | Online | [www.rainbowhospice.org/](http://www.rainbowhospice.org/) |
| Statewide | Angels Grace Hospice | Online | [www.angelsgracehospice.com/](http://www.angelsgracehospice.com/) |
| Nationwide | Heartland Hospice | Online | [www.heartlandhospice.com/](http://www.heartlandhospice.com/) |

|  |
| --- |
| 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/](http://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 | HDSA Long Term Care publication | Book | <http://hdsa.org/wp-content/uploads/2015/05/long->term-care.pdf |
| Statewide | Illinois Peer Coalition | Online | https://illinoispioneercoalition.org |
| Statewide | Elderwerks | 855-462-0100 | [www.elderwerks.com](http://www.elderwerks.com/) |
| Statewide | A Place for Mom | Online | A free referral service helping families find nursinghomes, assisted living, retirement communities, home care and other living options. [www.aplaceformom.com](http://www.aplaceformom.com/) |
| Statewide | IL Department of Public Health | Online | [www.idph.state.il.us/healthca/](http://www.idph.state.il.us/healthca/)nursinghometestjava.htm |
| Statewide | IL Council on Long Term Care | 773-478-6613 | [www.nursinghome.org/how.html](http://www.nursinghome.org/how.html) |
| Statewide | Illinois Citizens for Better Care- nursing home advocates | 312-663-5120 | [http://www.illinoiscares.org](http://www.illinoiscares.org/) |

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 | https://[www.illinois.gov/hfs/](http://www.illinois.gov/hfs/)MedicalClients/HCBS/Pages/slf.aspx |
| Statewide | Assisted Senior Living | Online | [www.assistedseniorliving.net/](http://www.assistedseniorliving.net/)services/illinois/ |
| Statewide | Eden Supportive Living: provides supportive living to people with disabilities age 22-64 | Call Individual location | [www.edensupportiveliving.com/](http://www.edensupportiveliving.com/) |
| Statewide | Deer Path Supportive Living for people age 22-64 | 847-515-1800 | [www.bma-mgmt.com/](http://www.bma-mgmt.com/)deerpathhuntley/ |
| Nationwide | Care Pathways | Online | [www.carepathways.com/](http://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](http://www.medicare.gov/nhcompare) and always visit first, unannounced, to observe how the living community is run.

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Aledo, IL | Aledo Nursing & Rehab | 309-691-8113 | [www.petersenhealthcare.net/aledo/](http://www.petersenhealthcare.net/aledo/) |
| Anderson, IN | Edgewater Woods | 888-996-8272 | [www.ascseniorcare.com/edgewater-](http://www.ascseniorcare.com/edgewater-)woods/ |
| Arcola, IL | Arcola Healthcare & Rehab | 217-268-3022 | [www.petersenhealthcare.net/arcola/](http://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/](http://www.jenningsterrace.com/) |
| Aurora, IL | North Aurora Care Center | 630-892-7627 | [www.petersenhealthcare.net/north-](http://www.petersenhealthcare.net/north-)aurora/ |
| Aviston, IL | Aviston Countryside Manor | 618-228-7615 | Call for information |
| Batavia, IL | Batavia Rehab and Healthcare | 630-879-5266 | [www.petersenhealthcare.net/batavia/](http://www.petersenhealthcare.net/batavia/) |
| Bloomingdale, IL | West Suburban Nursing and Rehab | 630-894-7400 | [www.wsnrc.com/](http://www.wsnrc.com/) |
| Brighton, IL | Robings Manor | 618-691-8113 | [www.petersenhealthcare.net/robings-](http://www.petersenhealthcare.net/robings-)manor/ |
| Burnsville, MN | Sonshine and Hope Home for HD | 612-203-2284 | [www.sonshineandhope.com/](http://www.sonshineandhope.com/) |
| Cloverdale, IN | Summerfield Healthcare Nursing Home | 765-795-4260 | http://summerfieldhealthcarecenter.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 managment often changes. Please check their quality rating on [www.medicare.gov/nhcompare](http://www.medicare.gov/nhcompare) and always visit first, unannounced, to observe how the living community is run.

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Chicago, IL | Bethesda Home | 773-622-6144 | [www.bethesdahome.com/](http://www.bethesdahome.com/) |
| Chicago, IL | Buckingham Pavilion | 773-973-5333 | [www.buckinghampavilion.com/](http://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/](http://www.arbourhealthcare.com/) |
| Chicago, IL | All American Nursing Home | 773-334-2224 | [www.allamericannursing.com/](http://www.allamericannursing.com/) |
| Chicago, IL | Clark Manor Convalescent Center | 773-338-8778 | [http://www.clarkmanorchicago.com](http://www.clarkmanorchicago.com/) |
| Chicago, IL | Norwood Crossing | 773-577-5323 | [www.norwoodcrossing.org/](http://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](http://www.aldentownmanor.com/) |
| Effingham, IL | Evergreen Nursing and Rehab | 1-800-385-2527 | [http://evergreennursingrehab.com](http://evergreennursingrehab.com/) |
| Elletssviille, IN | Richard-Blossom Health Care | 812-876-6400 | [http://www.rbbhcc.com](http://www.rbbhcc.com/) |
| Elmhurst, Il | The Grove of Elmhurst | 630-530-5225 | [http://groveelmhurst.com](http://groveelmhurst.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 managment often changes. Please check their quality rating on [www.medicare.gov/nhcompare](http://www.medicare.gov/nhcompare) and always visit first, unannounced, to observe how the living community is run.

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Evanston, IL | The Grove of Evanston | 847-316-3320 | https://[www.thegroveofevanston.com](http://www.thegroveofevanston.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/](http://www.twincity-healthcare.com/) |
| Geneva, IL | Bria of Geneva | 847-933-9200 | https://briahs.com/location/geneva/ |
| Kenosha Estates Living and Care Center | Kenosha, Wisconsin | 262-658-4125 | [http://www.kenoshaestatesrcc.com](http://www.kenoshaestatesrcc.com/) |
| Kewanee, IL | Royal Oaks Care Center | 309-691-8113 | https://[www.petersenhealthcare.net/royal-](http://www.petersenhealthcare.net/royal-)oaks/ |
| Knoxville, IL | Knox County Nursing Home | 309-289-2338 | https://[www.knoxcountynursinghome.com/](http://www.knoxcountynursinghome.com/)contact-us/ |
| Lake Zurich, IL | Lexington Health | 877-637-4803 | [www.lexingtonhealth.com/](http://www.lexingtonhealth.com/) |
| Libertyville, IL | Thrive Long Term and Memory Care | 847-377-7200 | https://thriveahead.com/winchester-house/ |
| Lindenhurst, IL | Village at Victory Lakes | 847-356-5900 | https://[www.franciscanministries.org/](http://www.franciscanministries.org/)victory-lakes/ |
| Long Grove, IL | Alden Long Grove | 847-438-8275 | [www.aldenlonggrove.com/](http://www.aldenlonggrove.com/) |
| Mattoon, IL | Palm Terrace | 217-234-7403 | [www.petersenhealthcare.net/palm-terrace/](http://www.petersenhealthcare.net/palm-terrace/) |
| Moline, IL | Heartland | 309-764-6744 | https://[www.heartland-manorcare.com/](http://www.heartland-manorcare.com/)locations/heartland-health-care-center- moline/? contentIdString=14062&contentNameString=Contact%20Us |

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 managment often changes. Please check their quality rating on [www.medicare.gov/nhcompare](http://www.medicare.gov/nhcompare) and always visit first, unannounced, to observe how the living community is run.

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Naperville, IL | Alden Estates | 630-983-0300 | [www.aldenestatesofnaperville.com/](http://www.aldenestatesofnaperville.com/) |
| Naperville, IL | St. Patrick’s Residence | 630-416-6565 | [www.stpatricksresidence.org/](http://www.stpatricksresidence.org/) |
| Niles, IL | Niles Nursing and Rehab Center | 847-967-7000 | [www.nilesnursing.com/](http://www.nilesnursing.com/) |
| North Aurora | North Aurora Care Center | 630-892-7627 | https://[www.petersenhealthcare.net/north-](http://www.petersenhealthcare.net/north-)aurora/ |
| Orland Park, IL | Alden Estates | 708-403-6500 | [www.aldenestatesoforlandpark.com/](http://www.aldenestatesoforlandpark.com/) |
| Palos Park, IL | Sunrise | 888-434-4648 | [www.sunriseseniorliving.com](http://www.sunriseseniorliving.com/) |
| Peoria, IL | Sharon Healthcare Pines | 309-688-0350 | [www.sharonhealthcarepines.com/](http://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/> |
| Prophetstown | Winning Wheels | 815-537-5168 | [www.winningwheels.com/](http://www.winningwheels.com/) |
| Richmond, MN | Tadd’s Lighthouse | 612-643-5360 | <http://taddslighthouse.com/> |
| Robbinsville, MN | University of Good Samaritan | 866-928-1635 | https://[www.good-sam.com/services/rehab-](http://www.good-sam.com/services/rehab-)skilled-care/huntingtons-disease-care |
| Rock Falls, IL | Rock Falls Rehabilitation | 309-691-8113 | https://[www.petersenhealthcare.net/rock-falls/](http://www.petersenhealthcare.net/rock-falls/) |
| Rockford, IL | Alden Park Strathmoor | 815-229-5200 | [www.aldenparkstrathmoor.com](http://www.aldenparkstrathmoor.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](http://www.medicare.gov/nhcompare) and always visit first, unannounced, to observe how the living community is run.

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Rolling Meadows, IL | Clearbrook ICF | 847-385-5018 | [www.clearbrook.org/](http://www.clearbrook.org/) |
| Rosiclare, IL | Rosiclare Nursing & Rehab | 309-691-8113 | [www.petersenhealthcare.net/rosiclare/](http://www.petersenhealthcare.net/rosiclare/) |
| Sheldon, IL | Sheldon Healthcare Center | 815-429-3134 | [www.petersenhealthcare.net/sheldon/](http://www.petersenhealthcare.net/sheldon/) |
| Skokie, IL | The Grove of Skokie | 847-679-2322 | [http://thegroveofskokie.com](http://thegroveofskokie.com/) |
| Sterling, IL | Regency Care of Sterling | 815-626-9020 | https://regencycaresterling.com |
| Sterline | Rock River Gardens | 815-626-2333 | https://[www.petersenhealthcare.net/rock-](http://www.petersenhealthcare.net/rock-)river/ |
| Vernon Hills, IL | Brookdale Assisted Living | 847-793-0793 | https://[www.brookdale.com/en/](http://www.brookdale.com/en/)communities/brookdale-vernon-hills.html |
| Wheaton, IL | DuPage Convalescent Center | 630-665-6400 | [www.dupageco.org/Convalescent\_Center/](http://www.dupageco.org/Convalescent_Center/)6086/ |
| Wilmette | Sunrise of Wilmette | 224-563-1743 | https://[www.sunriseseniorliving.com/](http://www.sunriseseniorliving.com/)communities/sunrise-of-wilmette/ overview.aspx |
| Willowbrook, IL | Chateau of Willowbrook | 630-323-6380 | https://chateaucenter.com |
| Winchester, IN | Randolph Nursing Home | 765-584-2201 | https://[www.sunriseseniorliving.com/](http://www.sunriseseniorliving.com/)communities/sunrise-of-wilmette/ overview.aspx |
| Yorkville, IL | Hillside Healthcare and Rehab | 844-264-3258 | <http://www.heliahealthcare.com/hillside/> |
| Specialty Unit in New York dedicated to HD | Terrence Cardinal Cook Health Center | 855-951-CARE | https://[www.archcare.org/specialized-care/](http://www.archcare.org/specialized-care/)huntingtons-disease |
|  |  |  |  |

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 | Shield Healthcare | 800.675.8847 | [www.shieldhealthcare.com/](http://www.shieldhealthcare.com/) |
| Statewide | Simon Foundation Diaper Bank | Online | [www.simonfoundation.org/](http://www.simonfoundation.org/)Diaper\_Banks.html |
| Statewide | Home Products for Seniors | 800-425-1101 x103 | <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](http://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](http://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/](http://www.rightathome.net/states/illinois/) |
| Nationwide | Comfort Keepers | 800-387-2415 | [www.comfortkeepers.com/](http://www.comfortkeepers.com/) |
| Nationwide | Home Instead | 800-640-3914 | [www.homeinstead.com/Pages/home.aspx](http://www.homeinstead.com/Pages/home.aspx) |
| Statewide | Services for Adults Staying in Their Homes (SASI) | 847-864-7274 | [www.sasiathome.org/](http://www.sasiathome.org/) |
| Statewide | Wellspring Personal Care | 312-648-1565 | <http://homecarechicago.com/> |
| Nationwide | Care Pathways | Online | [www.carepathways.com/](http://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](http://www.healthcare.gov/) |
| Nationwide | Cost of insurance plan calculator | Online | <http://kff.org/interactive/subsidy-calculator/> |
| Statewide | Illinois Health Matters | Online | <http://illinoishealthmatters.blogspot.com/> |
| Statewide | Illinois Health Care Options | Publication | [www.coverageforall.org/pdf/matrix/](http://www.coverageforall.org/pdf/matrix/)IL\_Matrix.pdf |
| Statewide | Illinois SHIP (Help with Medicare) | Online | https://www2.illinois.gov/aging/ship/Pages/default.aspx |
| Cook County, IL | County Care | 312-864-8200 | <http://countycare.com/> |
| Nationwide | Medicare | 800-772-1213 | [www.medicare.gov](http://www.medicare.gov/) |
| Nationwide | Patient Advocate Foundation | Online | [www.patientadvocate.org/index.php](http://www.patientadvocate.org/index.php) |

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

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Nationwide | American Association for Long Term Care Insurance | 818-597-3227 | [www.aaltci.org/long-term-care-insurance/](http://www.aaltci.org/long-term-care-insurance/) |
| Statewide | Illinois Health Matters | Online | <http://illinoishealthmatters.org/> |
| Statewide | Your Benefits Advocate- Susan Loeb | 773-684-9802 | [www.yourbenefitsadvocate.com/](http://www.yourbenefitsadvocate.com/) |
| Nationwide | Jan L. Kodner & Associates | 312-922-6688 | [www.mysocialsecuritylawyer.com](http://www.mysocialsecuritylawyer.com/) |
| Statewide | Common Medicaid Mistakes | Online | <http://tinyurl.com/9we2eqc> |
| Nationwide | Affordable Care Act Tipsheets | Online | [www.ageoptions.org/services-and-](http://www.ageoptions.org/services-and-)programs\_AffordableCareActTipSheets.html |
| Nationwide | Extra Help Program | 800-772-1213 | [www.ssa.gov/prescriptionhelp/](http://www.ssa.gov/prescriptionhelp/) |
| Nationwide | Medicare Savings Program | 800-843-6154 | <http://tinyurl.com/khc5upv> |

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](http://www.patientadvocate.org/index.php) |
| Nationwide | Legal Planning Guide | Online | https://[www.nhpco.org/patients-and-](http://www.nhpco.org/patients-and-)caregivers/advance-care-planning/ |
| Statewide- Cook Co. | Center for Disability and Elder Law | 312-376-1880 | [www.cdelaw.org](http://www.cdelaw.org/) |
| Statewide | Equip for Equality | 312-223-9600 | [www.equipforequality.org/programs/](http://www.equipforequality.org/programs/) |
| Statewide | Illinois Guardianship and Advocacy Commission | 866-274-8023 | [www.gac.state.il.us/](http://www.gac.state.il.us/) |
| Statewide | Law Elder Law, LLP- Attorneys for eldercare, estate planning, etc | 800-810-3100 | [www.lawelderlaw.com/](http://www.lawelderlaw.com/) |
| Statewide | Teresa Nuccio- Attorney for estate planning and special needs | 312-621-5239 | https://[www.harrisonheld.com/](http://www.harrisonheld.com/)professionals/teresa-nuccio/ |
| Statewide | Dutton and Casey- Elder Law/Special Needs Attorneys | Erin Vogt (social worker): 312-899-0950 | [www.duttonelderlaw.com/](http://www.duttonelderlaw.com/) |
| Statewide | Heartland Law | 847-729-3300 | [www.heartlandlawfirm.com/](http://www.heartlandlawfirm.com/) |
| Statewide | Bill Wilson Elder Law | 708-482-7090 | [www.lagrangelaw.com/](http://www.lagrangelaw.com/) |
| Statewide | Your Benefits Advocate- Susan Loeb | 312-860-7417 | [www.yourbenefitsadvocate.com](http://www.yourbenefitsadvocate.com/) |
| Statewide | Jefrey A. Rabin and Associates | 847-299-0008 | [www.RabinSSlaw.com](http://www.RabinSSlaw.com/) |

|  |  |  |  |
| --- | --- | --- | --- |
| **Location** | **Name** | **Contact** | **Website** |
| Statewide | Peck and Bloom, LLC | 312-201-0900 | [www.peckbloom.com/](http://www.peckbloom.com/) |
| Statewide | Chicago Volunteer Legal Services | 312-332-1624 | [www.cvls.org/](http://www.cvls.org/) |
| Statewide | Chicago Legal Clinic | 312-726-2938 | [www.clclaw.org/](http://www.clclaw.org/) |
| Statewide | Catholic Charities | 312-948-6821 | https://[www.catholiccharities.net/](http://www.catholiccharities.net/)GetHelp/OurServices/LegalServices/ CCLA.aspx |
| Statewide | Coordinated Advice and Referral Program for Legal Services | 312-738-9200 | [www.carpls.org/](http://www.carpls.org/) |
| Statewide | Legal Aid Chicago | Online | https://[www.legalaidchicago.org](http://www.legalaidchicago.org/) |
| Statewide | James C. Siebert & Associates | 847-253-7500 | [www.jcslaw.com](http://www.jcslaw.com/) |
| Statewide | Jenette M. Scwemler | 815-245-4665 | [www.jms-attorney.com](http://www.jms-attorney.com/) |
| Statewide | Michling, Hofmann, Plaza & Wick | 815-338-9600 | [www.woodstocklawpros.com/](http://www.woodstocklawpros.com/) |
| Statewide | Law Offices of Gary R. Waitzman | 847-719-1300 | [www.grweplaw.com/](http://www.grweplaw.com/) |
| Statewide | Northern Illinois Center for ElderCARE, P.C. | 815-227-1144 | [www.elderlawrockford.com/](http://www.elderlawrockford.com/) |
| Statewide | Strohschein Law Group | 630-377-3241 | [www.strohscheinlawgroup.com](http://www.strohscheinlawgroup.com/) |
| Statewide | Law Office of Kate Curler | 312-952-1077 | [www.curlerlaw.com](http://www.curlerlaw.com/) |
| Statewide | Law Offices of Anthony B. Ferraro | 847-221-0154 | [www.abferrarolaw.com](http://www.abferrarolaw.com/) |
| Statewide | Zukowski, Rogers, Flood & McArdle | 815-459-2050 | [www.zrfmlaw.com](http://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 | https://hdsa.org/living-with-hd/gina/ |
| Nationwide | National Association of Insurance and Financial Advisors | Online | https://belong.naifa.org |
| Nationwide | Life Happens | Online | https://lifehappens.org/life-insurance-101/ |
| Nationwide | Whole life insurance with no medical review | Online | https://[www.unitedhomelife.com](http://www.unitedhomelife.com/) |
| Nationwide | Impaired-risk specialist info | Online | [www.insure.com/articles/lifeinsurance/](http://www.insure.com/articles/lifeinsurance/)special-risk.html |
| Nationwide | How to buy life insurance | Online | [www.nolo.com/legal-encyclopedia/](http://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/](http://www.bankrate.com/finance/insurance/)10-questions-life-insurance- agent-1.aspx |
| Nationwide | MetLife Special Needs Planners | Online | https://[www.metlife.com/blog/money/](http://www.metlife.com/blog/money/)special-needs-families/ |

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 | https://hdsa.org/living-with-hd/long-term-care/ |
| Nationwide | Shopper’s Guide to LTC insurance | Online | https://[www.ltcfeds.com](http://www.ltcfeds.com/) |
| Nationwide | Elder Law Answers | Online | [www.elderlawanswers.com/long-term-](http://www.elderlawanswers.com/long-term-)care-insurance |
| Nationwide | Administration on Aging | Online | [www.longtermcare.gov](http://www.longtermcare.gov/) |
| Nationwide | New & Unexpected Ways to Fund LTC | Online | [www.forbes.com/sites/jamiehopkins/](http://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-](http://www.genworth.com/corporate/about-)genworth/industry-expertise/cost-of- care.html |
| Nationwide | John Hancock | Online | [www.johnhancock.com/products/long-](http://www.johnhancock.com/products/long-)term-care.html |
| Nationwide | Mutual of Omaha | Online | [www.mutualofomaha.com/long-term-](http://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-](http://www.ageoptions.org/services-and-)programs\_ABEToolkit.html |
| Statewide | Care Coordination Expansion Map | Online | https://[www.illinois.gov/hfs/](http://www.illinois.gov/hfs/)MedicalProviders/cc/Pages/ CareCoordinationExpansion.aspx |
| 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 | Dual Eligible MMAI Program | Online | [www.ageoptions.org/documents/](http://www.ageoptions.org/documents/)1.MMAIWebinar-ADRN5114.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/](http://www.medicalalertcomparison.com/) |
| Nationwide | Medical Alert Reviews- compare companies | Online | [http://medical-alert-systems-](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/](http://www.medicalguardian.com/) |
| Nationwide | Alert1 | 1-866-299-0605 | <http://www.alert-1.com/> |
| Nationwide | Life Alert | 1-800-360-0329 | [http://www.lifealert.com](http://www.lifealert.com/) |
| Nationwide | ADT | 1-800-588-0023 | https://[www.adt.com/health?](http://www.adt.com/health)ecid=H\_DM\_BPS\_ADT\_GOO\_G-H-B- ADT-Medical- Acq&gclid=Cj0KCQjw8fr7BRDSARIsA K0Qqr79KppUfam4VzWjtnKrRY-1oD amnOc3Qv2TPGtOgORp9ku\_CPDqR 9waAv5TEALw\_wcB |
| 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) | 708-754-9575 | https://ourtchfoundation.org |
| Nationwide | Broda Seating | 844-552-7632 | https://brodaseating.com |
| Nationwide | In Step Mobility Products, Inc | 800-558-7837 | [www.ustep.com/](http://www.ustep.com/) |
| Nationwide | Philips Lifeline- medic alert necklace | 855-681-5351 | [www.lifelinesys.com/content/home](http://www.lifelinesys.com/content/home) |
| Nationwide | Care Foam | 1-866-332-3356 | [www.carefoam.com/](http://www.carefoam.com/) |
| Nationwide | Apria Healthcare | 1-888-492-7742 | [www.apria.com](http://www.apria.com/) |
| Nationwide | North Coast Medical | 800-821-9319 | [www.ncmedical.com/](http://www.ncmedical.com/) |
| Nationwide | Patterson Medical | 800-323-5547 | [www.pattersonmedical.com/](http://www.pattersonmedical.com/) |
| Nationwide | Gold Violin | 1-800-458-2000 | <http://goldviolin.blair.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 | Home Sensors for Stove | 877-785-9901 | [www.homesensers.com/](http://www.homesensers.com/) |
| Nationwide | Guardian- Strider Walker | 1-800-827-8283 | [www.rehabmart.com/product/guardian-](http://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/](http://www.best-priced-products.com/) |
| Nationwide | Gunnel, Inc (chairs) | 800-551-0055 | [www.gunnell-inc.com/](http://www.gunnell-inc.com/) |
| Nationwide | Alimed (cushions, support, eating utensils, padding) | 800-225-2610 | [www.alimed.com/](http://www.alimed.com/) |
| Nationwide | NOA Medical (Beds and bedding accessories) | 800-663-6068 | [www.noamedical.com/](http://www.noamedical.com/) |
| Statewide | Ramp Now (ramps and lifts) | 630-892-7267 | [www.rampnow.com](http://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 | 800-522-6294 | [www.assistech.com/products/](http://www.assistech.com/products/)Products-for-Memory-Loss/-Cognitive- Disorders.htm |
| Statewide | Illinois Assistive Technology Program- Device Loan Program | 1-800-852-5110 | https://[www.iltech.org](http://www.iltech.org/) |
| Nationwide | Rest Assured- online communication between working caregiver and loved one at home | 1-877-338-9193 | https://restassured.com |
| Nationwide | Disposable toilet floor mats | Online | [www.webstaurantstore.com/search/](http://www.webstaurantstore.com/search/)disposible-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 |

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 | 1-800-633-4227 | [www.medicare.gov](http://www.medicare.gov/) |
| Statewide | Senior Health Insurance Program | 1-800-252-8966 | [www.cbrx.il.gov/aging/1news\_pubs/](http://www.cbrx.il.gov/aging/1news_pubs/)publications/SHIPBrochureEnglish.pdf |
| Statewide | Senior Health Assistance Program | Online | [www.state.il.us/aging/1directory/shap.pdf](http://www.state.il.us/aging/1directory/shap.pdf) |
| Nationwide | Understanding Medicare | Online | https://[www.medicare.gov/Pubs/pdf/11219-](http://www.medicare.gov/Pubs/pdf/11219-)Understanding-Medicare-Part-C-D.pdf |
| Nationwide | Extra Help Program |  | [www.ssa.gov/prescriptionhelp/](http://www.ssa.gov/prescriptionhelp/) |
| Nationwide | Medicare Savings Program | 800-843-6154 | <http://tinyurl.com/khc5upv> |
| Nationwide | Medicare Observation Status | Online | [www.medicareadvocacy.org/self-help-packet-](http://www.medicareadvocacy.org/self-help-packet-)for-medicare-observation-status |
| Nationwide | Eligibility and Premium Calculator | Online | [www.medicare.gov/eligibilitypremiumcalc/](http://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 | Medicare Self Help Kit | Online | [www.medicareadvocacy.org/self-help-packet-](http://www.medicareadvocacy.org/self-help-packet-)for-medicare-observation-status/ |
| Nationwide | Kaiser Foundation FAQ | Online | <http://tinyurl.com/mtkza34> |

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 | 1-800-503-6897 | [www.needymeds.org](http://www.needymeds.org/) |
| Nationwide | Rx Assist | Online | [www.rxassist.org](http://www.rxassist.org/) |
| Nationwide | Medical Assistance Tool |  | [www.pparx.org/](http://www.pparx.org/) |
| Nationwide | HD Drugworks | Online | hddrugworks.org |
| Nationwide | PharmacyChecker.com | Online | Compare Rx prices for medication; see pharmacy ratingsand shipping fees: [www.pharmacychecker.com](http://www.pharmacychecker.com/) |
| Statewide | IL Rx Buying Club for the uninsured | 866-215-3462 | https://[www.rxresource.org/prescription-assistance/](http://www.rxresource.org/prescription-assistance/)illinois-rx-buying-club.html |
| Nationwide | Senior Health Insurance Program (SHIP) | 1-800-252-8966 | Assistance with choosing appropriate Medicare Part DPlan: https://www2.illinois.gov/aging/ship/Pages/ default.aspx |
| Nationwide | Lundbeck, Xenazine USA | 888-882-6013 | https://[www.xenazineusa.com](http://www.xenazineusa.com/) |
| Nationwide | Medicare Interactive- Formulary Tier Exception | Online | [www.medicareinteractive.org/page2.php?](http://www.medicareinteractive.org/page2.php)topic=counselor&page=script&slide\_id=1738 |

(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 |  | [www.dhs.state.il.us/page.aspx?](http://www.dhs.state.il.us/page.aspx)item=29728 |
| Statewide | IL NAMI (National Alliance on Mental Illness | 1-800-950-6264 | https://namiillinois.org |
| Nationwide | What Families Need to Know about Hospitalization | Booklet | <http://tinyurl.com/l6aasxy> |
| Nationwide | Mental Illness and Hospitalization | Online | [www.mentalhealthamerica.net](http://www.mentalhealthamerica.net/)/is-hospitalization-necessary |
| Statewide | Thresholds | 773-572-5500 | [www.thresholds.org/](http://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](http://www.renettedavis.com/nutritn.html) |
| Nationwide | Locating a dietician | Online | https://[www.eatright.org](http://www.eatright.org/) |
| Nationwide | HDSA Nutrition and HD | Online | https://hdsa.org/find-help/living-well-with-hd/nutrition/ |
| Nationwide | Book for people with swallowing difficulties | Online | [www.amazon.com/Easy-Swallow-](http://www.amazon.com/Easy-Swallow-)Chew-Cookbook-Nutritious/dp/ 0471200743 |
| Nationwide | Ensure Nutritional Shakes (Abbott) Patient Assistance Program | 800-222-6885 | <http://static.abbottnutrition.com/>cms-prod/ pathwayreimbursement.com/img/ PAP%20Application%20Final.pdf |

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 | <http://hdsa.org/wp-content/>uploads/2015/03/ PhysicalOccupationalTherapy\_Famil yGuide.pdf |
| Nationwide | OT Locator via Healthgrades | Online | [www.healthgrades.com/](http://www.healthgrades.com/) |

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 | 773-728-6336 | [www.touchedbyananimal.org/](http://www.touchedbyananimal.org/) |
| Statewide | Anti-cruelty Society |  | [www.anticruelty.org/](http://www.anticruelty.org/) |
| Statewide | Animal Welfare League | 708-636-8586 | [www.animalwelfareleague.com/](http://www.animalwelfareleague.com/) |
| Statewide | Banfield Charitable Trust | Online | https://[www.banfield.com/](http://www.banfield.com/)banfield-foundation/resources |
| Statewide | Felines | 773-465-4132 | [www.felinescanines.org/](http://www.felinescanines.org/) |
| Statewide | PAWS |  | [www.pawschicago.org](http://www.pawschicago.org/) |
| Statewide | Tree House Animal Foundation | 773-262-4000 | [www.treehouseanimals.org/](http://www.treehouseanimals.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/](http://www.apta.org/apta/findapt/)index.aspx?navID=10737422525 |
| Nationwide | HDSA Physical Therapy Guide | Online | \<http://hdsa.org/wp-content/>uploads/2015/03/ PhysicalOccupationalTherapy\_Famil yGuide.pdf |
| Nationwide | HDSA Convention Presentation on PT | Online | https://hdsa.org/wp-content/uploads/2015/02/Physical-Therapy- and-Huntington-s-Disease-kloos.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/](http://www.archrespite.org/) |
| Statewide | Illinois Respite Coalition | 630-207-8479 | http://[www.illinoisrespitecoalition.org/](http://www.illinoisrespitecoalition.org/) contact-il-legislators.html |
| Statewide | IL Dept on Aging Caregiver Program (60yrs+) | 800-252-8966 | [www.state.il.us/aging/1caregivers/](http://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?](http://www.dhs.state.il.us/page.aspx)item=29738 |

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-](http://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?](http://www.dhs.state.il.us/page.aspx)item=29738 |
| Chicago | Mayors Office for People with Disabilities | 312-744-7050 | [www.cityofchicago.org/city/en/](http://www.cityofchicago.org/city/en/)depts/mopd.html |
| Statewide | IL Dept. on Aging Community Care Program- financial eligibility | 800-252-8966 | https://www2.illinois.gov/aging/BenefitsAccess/Pages/ Eligibility%20and%20Frequently- Asked-Questions.aspx |
| Statewide | Catholic Charities | 312-655-7700 | [www.catholiccharities.net/](http://www.catholiccharities.net/) |
| Statewide | Habilitating Hands medical case management | 312-494-5797 | [www.habilitatinghands.com/](http://www.habilitatinghands.com/) |
| Nationwide | Job Accomodation Network | 800-526-7234 | [www.askjan.org/](http://www.askjan.org/) |
| Statewide | Centers for Independent Living | Online | [www.incil.org/](http://www.incil.org/) |
| Nationwide | Eldercare Consultants- Planning | 773-508-1015 | [www.youreldercareconsultants.com](http://www.youreldercareconsultants.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/](http://www.asha.org/findpro/) |
| Nationwide | Coping with Speech and Swallowing Difficulties | Online | <http://hdsa.org/wp-content/>uploads/2015/03/Speech- Language-Swallowing- Difficulties.pdf |
| Nationwide | American Speech Language Hearing Association | Online | https://[www.asha.org](http://www.asha.org/) |
| Nationwide | HDSA Speech Therapy presentation | Online | <http://hdsa.org/wp-content/>uploads/2016/06/HDSA-workshop- presentation2016-speech- pathology.pdf |
| International | Communication and HD | Online | [www.huntingtonswa.org.au/](http://www.huntingtonswa.org.au/)information/living-with-hd/ communication-and-hd/ |
| International | Swallowing and HD | Online | [www.huntingtonswa.org.au/](http://www.huntingtonswa.org.au/)information/living-with-hd/ swallowing-and-hd/ |
| Nationwide | HDSA Nutrition Guide | Online | https://hdsa.org/find-help/living-well-with-hd/nutrition/ |

#  Support Groups in Illinois

**70**

changes and obstacles.

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

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Location** | **Details** | **Location** | **Contact** | **Location** |
| Bloomington | Virtual dates - 4th Sunday of the month, 2-3:30 | Central Illinois | Larry Haigh larryhaigh@gmail.com or 815-383-1877 | St. Joseph Medical CenterBusi. Conf. Center Rm 2 2200 E. Washington St. Bloomington, IL |
| Rush University Medical Center, Chicago | Virtual dates: 3rd Saturday of the month, 10-12 | Rush University Medical Center, Chicago | Key’Aira Glasper, Rush Social Workeror 312 942-6000 X 27915 orKeyAira\_Glasper@rush.edu | Rush Univ. Medical CenterTower Resource Center (Tower, 4th Floor, Suite 04527) 1620 W. Harrison Street, Chicago |
| Northwestern Medicine, Chicago | Virtual dates: The 3rd Saturday of every month, 10-12 am | Northwestern Medicine, Chicago | Emily Zivin, Northwestern social worker, emily.zivin@northwestern.ed u or 312-926-8048 | Logan Square Library3030 W Fullerton Ave, Chicago, IL 60647Room: Conference Room |
| Geneva | Virtual Dates: 4th Sunday of the month, 2-3:30 | Geneva | Joe Wiedemann: 847-505-3933 | Delnor Hospital300 S. Randall Rd. Conference #4 of the 351 Medical Office Bldg. Geneva, IL |
| Libertyville | 2nd Monday of every month 7p | Lake County | Marilyn and Barry Kahn: 847- 975-2403marilynkahn1@gmail.com | Advocate Condell801 Milwaukee Ave West Tower Libertyville, IL |

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 | Virtual dates: 4th Sunday of the month, 2-3:30 | Charlotte Rybarczyk, charlotte82963@gmail.com | OSF St. Anthony Medical Center5666 E. State St. St. Anthony Room Rockford, IL |
| South Suburban | Virtual dates: The 3rd Saturday of every month, 10am-12 | Emily Zivin, ezivin@hdsa.org or 630-443-9876 | Thomas Cellini Huntington’sFoundation 3019 E. End AveSouth Chicago Heights |
| Munster, IN | 2nd Tues of even months at 7pm | Cindy Rogers: 219-680-6001 or clrogers111@comcast.net | Southside Christian Church1000 Broadmoor Ave Munster, IN |
| Caregiver Support group | 2021 Dates TBT | Emily Zivin, ezivin@hdsa or 630-443-9876 | Northfield Library1785 Orchard LaneNorthfield IL 60093 |

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 | Benefits Access Program (senior and disability free transit ride; license plate discount) | Online | https://www2.illinois.gov/aging/BenefitsAccess/pages/default.aspx |
| Nationwide | American Public Transportation |  | https://apta.com |
| Statewide | Pace Paratransit and Dial-a-RIde | 847-364-PACE (7223) | [www.pacebus.com/sub/paratransit/](http://www.pacebus.com/sub/paratransit/)default.asp |
| Statewide | Parking and other Publications and forms for people with disabilities | Online | [www.cyberdriveillinois.com/](http://www.cyberdriveillinois.com/)publications/disabilitypub.html |
| Statewide | Medicaid only- First Transit | 1-800-843-6154 | https://[www.dhs.state.il.us/](http://www.dhs.state.il.us/)page.aspx?item=47506 |

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/](http://www.accessunlimited.com/) |
| Nationwide | AMS Vans- wheelchair vans | 800-775-8267 | [www.amsvans.com/](http://www.amsvans.com/) |
| Nationwide | Finding Accessible Places: AXS Map | Online | [www.axsmap.com/](http://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) | 630-909-6080 | https://[www.marianjoy.org](http://www.marianjoy.org/) |
| Statewide | Rush Day Rehab (Chicago) | 1-888-352-7874 | https://[www.rush.edu/treatments/driving-](http://www.rush.edu/treatments/driving-)rehabilitation |
| Statewide | Alexian Brothers (Elk Grove Village, IL) | 1-855-692-6482 | https://[www.amitahealth.org/services/](http://www.amitahealth.org/services/)physical-medicine-and-rehabilitation/ occupational-therapy/ |
| Statewide | Institute for Physical Medicine and Rehabilitation (Peoria, IL) | 309-621-4111 | https://[www.osfhealthcare.org/practices/](http://www.osfhealthcare.org/practices/)28/1233/osf-rehabilitation/ |
| Statewide | Northshore (Evanston, IL) | 847-570-2000 | [www.northshore.org/physical-medicine-](http://www.northshore.org/physical-medicine-)rehabilitation/ |
| Statewide | IL Secretery of State-Medical Review Unit | 217-782-7246 | [www.cyberdriveillinois.com/departments/](http://www.cyberdriveillinois.com/departments/)drivers/drivers\_license/medical\_vision.html |
| Nationwide | Family Conversations about driving safety | Hartford Publication | https://[www.thehartford.com/resources/](http://www.thehartford.com/resources/)mature-market-excellence/dementia-driving |
| Nationwide | Example of a driving contract | Online | https://[www.alz.org/media/Documents/](http://www.alz.org/media/Documents/)alzheimers-dementia-driving-info-contract- ts.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-](http://www.tsa.gov/travel/passenger-)support |
| Nationwide | Flying Wheels Travel | Online | [http://www.disabledholidays4u.com/?](http://www.disabledholidays4u.com/)cms=details\_touroperator&pid=1506201111 2650 |
| Nationwide | Disabled Travelers | Online | [www.disabledtravelers.com/](http://www.disabledtravelers.com/)travel\_agents.htm |
| Nationwide | Rick Steves Travel Tips | Online | [www.ricksteves.com/travel-tips/trip-](http://www.ricksteves.com/travel-tips/trip-)planning/travelers-with-disabilities |
| Nationwide | Accessible Journeys | Online | <http://accessiblejourneys.com/> |
| Nationwide | Emerging Horizons | Online | [www.emerginghorizons.com/](http://www.emerginghorizons.com/) |
| Nationwide | Society for Accessible Travel and Hospitality | 212-447-7284 | [www.sath.org/](http://www.sath.org/) |
| Nationwide | Mobility International USA | 541-343-1284 | [www.miusa.org/](http://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 | https://[www.livhome.com/services/care-](http://www.livhome.com/services/care-)technology/ |
| Nationwide | Grand Care Systems | Online | [www.grandcare.com/](http://www.grandcare.com/) |
| Nationwide | Care Innovations | Online | [www.careinnovations.com/](http://www.careinnovations.com/) |
| Nationwide | Be Close | Online | <http://beclose.com/> |
| Nationwide | HealthSense | Online | [www.healthsense.com/](http://www.healthsense.com/) |
| Nationwide | 9 Need-to-know- Tech Must Haves for Caregivers | Online | <http://blog.aarp.org/2012/04/26/sally->abrahms-caregiving-technology-must-haves/ |

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 | 855-275-5237 | [www.jvschicago.org](http://www.jvschicago.org/) |
| Statewide | Illinois Assistive Technology Program | 217-522-7985 | https://[www.iltech.org](http://www.iltech.org/) |
| Statewide | Jane Addams Center for Working Families | 773-728-9769 | https://[www.jane-addams.org](http://www.jane-addams.org/) |
| Nationwide | National Able Network | Online | [www.nationalable.org](http://www.nationalable.org/) |
| Statewide | Aspire of Illinois | Online | https://aspirechicago.com |
| DuPage County | Worknet DuPage | Online | [www.worknetdupage.org/job-seekers/](http://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 | Jennifer Simpson: jsimpson@hdsa.org | https://nya.hdsa.org |
| International | Huntington’s Disease Youth Organization | Online | https://en.hdyo.org |
| Nationwide | Book: Talking to Kids about HD | Publication | <http://hdsa.org/product/talking-with-kids->about-hd/ |
| Statewide | SIBS- support for those with siblings with special needs | Online | [www.sibsnetwork.org/](http://www.sibsnetwork.org/) |
| Nationwide | Juvenile HD Handbook | Online | https://hdsa.org/product/the-juvenile-hd-handbook-a-guide-for-families-and- caregivers-2nd-edition/ |
| Nationwide | JHD and the School Experience | Online | <http://hdsa.org/wp-content/uploads/>2015/03/JuvenileHD\_School- Experience\_APR2015.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 | Online | [www.dreamfoundation.org/dream-](http://www.dreamfoundation.org/dream-)faq |
| Nationwide | Make a Wish | 800-978-9474 | [www.wishes.org/](http://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/](http://www.legacywriting.com/) |
| Nationwide | Comfort Dying: Books for Legacy Writing | Online | <http://www.comfortdying.com/>prayers poems and\_meditations\_61866.htm |
| Nationwide | Legacy Letter Project | Online | [www.legacyletterproject.com/](http://www.legacyletterproject.com/)legacy.html |
| Nationwide | Legacy Writing: A Spiritual Practice | Online | [www.drweil.com/drw/u/ART03239/](http://www.drweil.com/drw/u/ART03239/)Legacy-Writing-A-Spiritual- Practice.html |
| Nationwide | Emotional Legacy | Online | [www.emotionallegacy.com/](http://www.emotionallegacy.com/)legacywriting1.htm |