



Huntington's Disease Resources

State of California

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Introduction

This document was created to provide information on resources in California 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 California and nation-wide are ever-changing due to budget fluctuations and availability. Please contact the San Diego HDSA chapter family advocate, Doug Schulte dschulte91@outlook.com 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 share with Doug Schulte so it can be added.

Acknowledgment

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Adult Day Services

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

Location	Name	Contact	Website
Statewide	California Department of Aging	1-800-510-2020	https://www.aging.ca.gov/
Statewide/local	CA Association for Adult Day Services	916-552-7400	https://caads.org/about/
Local /San Diego County	Adult Day Resource Directory		https://sandiego.networkofcare.org/mh/services/advanced-search.aspx?k=%22Adult%20Day%20Health%20Programs%22

Advanced Directives, POLST, & Advanced Care Planning

You have the right to make decisions about your health care now and in the future. Advanced directives and POLSTs 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	California Advance Directive Form	Online	https://oag.ca.gov/sites/all/files/agweb/pdfs/consumers/ProbateCodeAdvancedHealthCareDirectiveForm-fillable.pdf
Nationwide	POLST – California Form	855-705-7845	https://polst.org/
Statewide	POLST – California Form	Online	https://capolst.org/
Nationwide	Advance Care Planning	Online	https://acpdecisions.org/
Nationwide	Advanced Care Discussion Guide	Online	https://mydirectives.com/en/help/conversation-starters/discussion-guide/
Statewide	California Department of Public Health	916-558-1784	https://www.cdph.ca.gov/
Statewide	San Diego End of Life Care Coalition	858-635-1224	https://sdcoalition.org/wordpresssite/
Nationwide	Compassion and Choices	800-247-7421	https://www.compassionandchoices.org/
Nationwide	National Hospice and Palliative Care Organization: Caring Info Resources	Online	https://www.nhpco.org/patients-and-caregivers/resources/

Aging and Disability Resource Network (ADRN)

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

Location	Name	Contact	Website
<p>CA Department on Aging: <i>Go here to locate your local Area Agency on Aging and they will connect you to the closest ARDN in your area</i></p>	<p>CA Dept on Aging</p>	<p>Online</p>	<p>https://www.aging.ca.gov/</p>

Books on HD and Coping with Illness

Below are some books about HD and coping with illness. HDSA does not endorse or recommend any books 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 Publications and Resource Library	https://hdsa.org/find-help/community-social-support/hdsa-resource-library/
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

Brain Donation

If you are contemplating brain donation, please reach out to the following agency 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. For more information go to <https://hdsa.org/news/hdsa-chdi-foundation-launch-hd-legacy-to-promote-brain-donation-for-hd-research>.

Location	Name	Contact	Website
Nationwide	Harvard Brain Tissue Resource Center <i>Brain donation for HD Research only</i>	McLean Hospital 115 Mill Street Belmont, MA 02478 800-272-4622 Fax: 617-855-3199	https://www.mcleanhospital.org/research/brain-bank
San Diego County	Legacy Funeral & Cremation Care <i>They work with HBTRC and facilitate the brain donation process</i>	7043 University Ave. La Mesa, Ca 91942 619-337-1400	https://legacyfuneralcare.com/

Caregiver Information and Support

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

Location	Name	Contact	Website
San Diego	HDSA San Diego Chapter Support Group	Online	http://san-diego.hdsa.org/about/hd-resources-in-san-dieg
Nationwide	HDSA Online Support Groups	Online	https://hdsa.org/find-help/community-social-support/hdsa-support-groups/
Nationwide	Family Care Alliance	Online	https://www.caregiver.org/
San Diego	Southern Caregiver Resource Center	858-268-4432	https://www.caregivercenter.org/
Statewide	Caregiver Resource Centers	Online	https://www.caregivercalifornia.org/
Nationwide	Caring From a Distance	Online	http://www.cfad.org/
Nationwide	Lotsa Helping Hands	Online	https://hdsa.lotsahelpinghands.com/info/

Counselors, Social Workers, and Therapists

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.

***Denotes Counselors and therapists that have HD experience.

Location	Name	Contact	Website
Local/San Diego***	Tracy Truscott, MSW, LCSW UCSD HD Center of Excellence	858-822-4800	https://medschool.ucsd.edu/so m/neurosciences/centers/huntingtons-disease/about/Pages/team.aspx
Nationwide***	HDSA Telehealth <i>8 free counseling sessions per year</i>	Online	https://hdsa.org/find-help/community-social-support/hdsa-telehealth/
Anywhere***	HD Internet Support Groups	Online	https://hdsa.org/find-help/community-social-support/hdsa-support-groups/
Local/San Diego County	Community Health Group – Medicare & Medi-Cal Providers	Online	https://providerdirectory.chgsd.com/
Local/San Diego***	Patricia Kelly Michals, LCSW, MFT	858-755-5687	http://www.sandiegotherapists.com/michals.html
Local/San Diego***	Healing Hearts Counseling Center – Jennifer Hill	Online	http://healingheartscounselingsd.com/faq/
Northern California***	University of California Davis- Lisa Mooney, LCSW	lmooney@ucdavis.edu	https://hdsa.org/hdsacoeucd/



Crisis Intervention

Crisis intervention is a time-limited intervention with a specific psychotherapeutic approach to immediately stabilize those in crisis.

Location	Name	Contact	Website
San Diego	Optum San Diego	888-724-7240 Crisis Hotline	https://www.optumsandiego.com/content/sandiego/en/access---crisis-line.html
San Diego	211 Crisis Intervention	760-757-3500 Crisis Hotline	https://my211.force.com/s/service/a1j2M000003rfUvQAI/crisis-intervention-and-hotline
San Diego County	PERT, Psychiatric Emergency Response Team <i>Provides emergency assistance and referral for individuals with a psychiatric crises. Pairs law enforcement with a mental health clinician to do at home crises evaluation.</i>	911 Ask for PERT	http://www.comresearch.org/pert.php
San Diego	DBSA, Depression and Bipolar Support Alliance	800-479-3339 Crisis Hotline	http://dbsasandiego.org/contact.html
San Diego County	Adult Protective Services	800-339-4661	https://www.sandiegocounty.gov/hsa/programs/ais/adult_protective_services/index.html
San Diego	Resource Access Program (RAP)	Online	https://www.sandiego.gov/fire/services/ems/rap
North Costal San Diego	Mobil Crisis Response Team (MCRT)	888-724-7240 Crisis Hotline	https://www.exodusrecovery.com/san-diego-mcrt/

End of Life Planning

Each family member makes a valuable contribution to the family...but when a family member dies how do the survivors cope? The purpose of this document is to motivate you to plan for an orderly transition. Eventually, someone will have to handle your affairs without you. Please sit down and fill out *Survivor's Guide: Take Time Now To Plan*. Preparation will ease the burden of your survivors

Location	Name	Contact	Website
Nationwide	Survivors Guide: Take Time Now To Plan	Online	https://drive.google.com/drive/folders/1bvK1AQLz6GfP49mL13mexNNDTaBIN7FR

Family Planning

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

Location	Name	Contact	Website
Nationwide	Stanford HOPES Family Planning Resources <i>Huntington's Outreach Project Education at Stanford</i>	Online	https://hopes.stanford.edu/family-planning/
Nationwide	Protected Tomorrows <i>Future Care Planning Re: education, residential, financial, legal, healthcare, benefits, employment and recreation</i>	847-522-8086	https://protectedtomorrows.com/
Nationwide	Having a Family ,The HD Way from HD Buzz	Online	https://en.hdbuzz.net/036
Nationwide	HelpCureHD <i>contributing financial, emotional, and mental support while trying to find the cure.</i>	Online	https://helpcurehd.org

Financial Benefits

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

Location	Name	Contact	Website
Nationwide	Benefits Checkup	Online	https://www.benefitscheckup.org/
Nationwide	PowerWallet Money Management	Online	https://www.powerwallet.com/app/register
Nationwide	Social Security Disability	800-772-1213	https://www.ssa.gov/applyfordisability/
Nationwide	Calculator to Check Your Estimated Social Security Benefits	Online	https://www.ssa.gov/benefits/calculators/
Nationwide	HDSA Disability Toolkit	Online	https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/
Statewide	Medi-Cal	800-541-5555	https://www.dhcs.ca.gov/services/Pages/Medi-CalManagedCare.aspx
Statewide	Genetically Handicapped Persons Program (financial assistance)	213-897-3574	https://www.dhcs.ca.gov/services/ghpp
Nationwide	Protected Tomorrows	847-522-8086	https://protectedtomorrows.com/
Nation wide & Statewide	Free Budgeting Assistance with Green Path	Online	https://secure.aadmm.com/

Financial/Special Needs Planning

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

Location	Name	Contact	Website
Nationwide	Protected Tomorrows	847-522-8086	https://protectedtommorrows.com/
Nationwide	American Association of Daily Money Managers	877-326-5991	https://secure.aadmm.com/
San Diego	Shannon O'Neil Jones, Attorney at Law Estate Planning, Trusts, Guardianship, Probate, Conservatorships & Adoption	619-222-5500	http://www.weberandoneill.com/
San Diego	Special Needs Planners San Diego	Online	https://specialneedsanswers.com/a-short-introduction-to-special-needs-planning-14593

Food and Nutrition

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	Eating Right; Academy of Nutrition and Dietetics	Online	https://www.eatright.org/
Nationwide	HDSA Nutrition and HD	Online	https://hdsa.org/?s=nutrition+and+HD
Nationwide	HDSA Nutrition Guide	Online	https://hdsa.org/?s=nutrition+guide
Nationwide	Book for people with swallowing difficulties	Online	https://www.amazon.com/Easy-Swallow-Chew-Cookbook-Nutritious/dp/0471200743
Nationwide	Ensure Nutritional Shakes (Abbott) Patient Assistance Program	866-801-5657	http://static.abbottnutrition.com/cms-prod/pathwayreimbursement.com/img/PAP%20Application%20Final.pdf

Food and Nutrition Assistance

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

Location	Name	Contact	Website
Statewide	Cal Fresh	Online	https://www.getcalfresh.org/?source=bing&msclkid=de56001ab4b710b156df5f4fb95f6114
San Diego	Meals on Wheels	Online	https://www.mealsonwheelsamerica.org/signup/aboutmealsonwheels/find-programs?filter=92103
San Diego	San Diego Food bank	866-350-3663	https://sandiegofoodbank.org/
San Diego County	Health and Human Services Agency	Online	https://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/community-resources-for-older-adults-during-covid-19/Non-ProfitFoodAssistance.html

Free Phones, Equipment, and Services

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

Location	Name	Contact	Website
Nationwide	Safelink Wireless	800-723-3546	https://www.safelinkwireless.com/Enrollment/Safelink/en/Web/www/default/index.html#!/newHome
Statewide	Your Call Wireless	Online	https://yourcallwireless.com/lifeline/
Nationwide	Reachout Wireless	Online	http://ww1.reachoutmobile.com/
Nationwide	Obama Phone	Online	https://www.obamaphone.com/
San Diego	Physical Therapy For All Free wheelchairs, walkers, etc.	949-735-995	https://www.ptforall.org/home.html
San Diego / Southern California	The Durable Medical Equipment Aid Society	818-298-9893	http://www.thedme.org/home

Funeral Planning

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 as well as resources that will guide you in funeral planning. To locate support groups specifically in your area, please contact Social Worker.

Location	Name	Contact	Website
Nationwide	Funeral/Arrangement Planning- My Way Forward	Online	https://www.mywayforward.com/
Nationwide	Death for Beginnings- Planning Guide	Online	http://deathforbeginners.com/
Nationwide	Planning a Funeral	Online	https://nfda.org/for-the-public/preplanning-a-funeral
Nationwide	The Light Beyond	Online	https://www.thelightbeyond.com/funeral_pre-planning_a_practical_matter.html
San Diego	Legacy Funeral & Cremation Care <i>They work with HBTRC and facilitate the brain donation process</i>	619-337-1400	https://legacyfuneralcare.com/

Genetic Counseling Centers in San Diego

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. 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 a Social Worker should you want to discuss further or want to process this difficult decision.

Location	Name	Contact	Website
San Diego	HD Center of Excellence, Dr Jody Corey-Bloom	858-249-0569	hd.ucsd.edu
San Diego	HD Genetic Test Information	Online	https://medschool.ucsd.edu/som/neurosciences/centers/huntingtons-disease/diagnosis-treatment/Pages/genetic-testing-counseling.aspx
Nationwide	Personal Essays on Genetics and Identity: Book on Genetic Disorders/Testing	Online	https://jhupbooks.press.jhu.edu/title/story-within

Genetic Discrimination

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
Nationwide	GINA (Genetic Non-Discrimination Act)	Online	https://en.wikipedia.org/wiki/Genetic_Information_Nondiscrimination_Act
Nationwide	HDSA GINA Tool Kit	Online	http://hdsa.org/living-with-hd/gina/
Nationwide	Gina Help	Online	http://www.ginahelp.org/
Nationwide	Coalition for Genetic Fairness	Online	http://www.geneticfairness.org/GINAPublication111008.pdf

Guardianship

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
San Diego	Shannon O'Neil Jones <i>Estate Planning, Trusts, Guardianship, Probate, Conservatorships & Adoption (HD Experience)</i>	619-222-5500	http://www.weberanddoneill.com/
Nationwide	National Guardianship Network	Online	https://www.nationalguardianshipnetwork.org/
Nationwide	National Guardianship Association	Online	https://www.guardianship.org/
Nationwide	ABA Commission on Law and Aging	Online	https://www.americanbar.org/groups/law_aging/resources/
Nationwide	Center for Elders and the Courts	Online	https://www.eldersandcourts.org/
Nationwide	National Academy of Elder Law Attorneys	Online	https://www.naela.org/Signin

HD Clinical Trials and Research Information

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

Name	Website
HDSA HD Trial Finder	https://www.hdtrialfinder.org/hdsa/home
European Huntington's Disease Network	http://www.euro-hd.net/
CHDI Foundation, Inc	https://chdifoundation.org/
HD Buzz- HD research in real person's language!	https://en.hdbuzz.net/
Huntington Study Group	https://huntingtonstudygroup.org/
HD: Hope Through Research: National Institute of Neurological Disorders and Strokes	https://www.ninds.nih.gov/Disorders/All-Disorders/Huntingtons-Disease-Information-Page
Stanford Hopes	https://hopes.stanford.edu/

HD Identification Resources

HD symptoms are often misinterpreted as someone under the influence or someone who is intentionally being uncooperative. The resources listed will aid in communicating important information to first responders and healthcare workers.

Location	Name	Contact	Website
San Diego County	Take Me Home Registry <i>The registry gives law enforcement quick access to critical information about a registered person with disabilities in case of an emergency</i>	Online	https://www.sdsheriff.net/tmh/
San Diego	HD Identification Cards <i>This picture ID can be used to verify HD symptoms when interacting with first responders</i>	dschulte91@outlook.com	
Nationwide	Medic Alert <i>Medical bracelets and necklaces</i> Medic Alert Sponsored Membership Form	800-432-5378	https://www.medicalert.org https://drive.google.com/drive/folders/1fUyvffp4SWPEGihqfZ8sX44-eWrlaptB
Nationwide	Vial of Life	Online	https://www.vialoflife.com/

HD Specific Resources

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

Name	Contact	Website
Huntington's Disease Society of America (HDSA)	800-345-4372	https://hdsa.org
HD Articles Divided by Topic	Online	http://hdsa.org/shop/publications/
Mayo Clinic Huntington's Information	On-line	https://www.mayoclinic.org/diseases-conditions/huntingtons-disease/symptoms-causes/syc-20356117
Huntington's Outreach Project for Education at Stanford (HOPES)	On-line	https://hopes.stanford.edu/
HSG: Huntington Study Group	On-line	https://huntingtonstudygroup.org/
HD Buzz	On-line	https://en.hdbuzz.net/
HDYO	On-line	https://en.hdyo.org/
Help 4HD International	On-line	https://www.help4hd.org/

Healthcare

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

Location	Name	Contact	Website
Statewide	Genetically Handicapped Persons Program (financial assistance)	213-897-3574	https://www.dhcs.ca.gov/services/ghpp
Statewide	Get Covered Help- free assistance	Online	https://www.coveredca.com/find-help/
Statewide	Covered California	Online	https://www.coveredca.com/
Nationwide	Cost of insurance plan calculator	Online	https://www.kff.org/interactive/subsidy-calculator/
Nationwide	Health Insurance Marketplace	Online	https://marketplace.cms.gov/
Nationwide	Medicare	800-772-1213	https://www.medicare.gov/
Nationwide	Patient Advocate Foundation	Online	https://www.patientadvocate.org/
Statewide	Ca Health Care Pre-Existing Conditions		https://www.calhealth.net/california_health_pre-existing_condition.htm
Nationwide	SSDI vs SSI	Online	https://www.ssa.gov/redbook/eng/overview-disability.htm
Nationwide	Medicare Parts C and D info	Online	https://www.healthline.com/health/medicare/medicare-part-c-vs-part-d
Statewide	Medi-Cal	Online	https://www.sandiego.gov/fire/services/ems/rap
Nationwide	Learning about Health Insurance	Online	https://marketplace.cms.gov/
Nationwide	American Association for Long Term Care Insurance	818-597-3227	https://www.aaltci.org/long-term-care-insurance/
Statewide	Common Medicaid Mistakes	Online	https://www.elderlawanswers.com/the-top-eight-mistakes-people-make-with-medicaid-4570
Nationwide	Extra Help Program	800-772-1213	https://www.ssa.gov/benefits/medicare/prescriptionhelp/
Nationwide	Medicare Savings Program	800-843-6154	https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/medicare-savings-programs
Nationwide	Same Sex Couples	Online	https://www.sageusa.org/

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Homeless Shelters

Homeless shelters provide temporary residence for homeless individuals and families. Shelters exist to provide residents with safety and protection from exposure to the weather while simultaneously reducing the environmental impact on the community.

Location	Name	Contact	Website
San Diego	San Diego Rescue Mission	619-819-1855	https://www.sdrescue.org/our-programs/
San Diego	Interfaith Shelters	619-702-5399	http://interfaithshelter.org/
San Diego	Father Joe's	619-446-2100	https://my.neighbor.org/our-solutions/
San Diego	Rachael's Women Center <i>759 Eighth Ave, San Diego, CA 92101</i>	619-696-0873	https://ccdsd.org/homeless-womens-services/
San Diego	San Diego Housing Commission	619-231-9400	https://www.sdhc.org/homelessness-solutions/city-homeless-shelters-services/
San Diego	211 Resources	211	https://211sandiego.org/resources/basic-needs/housing-information/

Home Health

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

Location	Name	Contact	Website
Nationwide	National Association for Home Care and Hospice	Online 202-547-7424	www.nahcagencylocator.com/
Nationwide	Home Health Compare: U.S. Dept of Health and Human Services, Centers for Medicare and Medicaid Services	800-633-4227	https://www.medicare.gov/care-compare/?providerType=HomeHealth&redirect=true
San Diego	Coast Care Partners	619-354-2544	https://coastcarepartners.com
Nationwide	American Academy of Home Care Medicine (house calls)	410-676-7966	https://www.aahcm.org/page/Locate_A_Provider

Home Modifications/Accessibility

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

Location	Name	Contact	Website
Nationwide	Independent Living Solutions	773-478-8450	http://www.ilsremodel.com/about-us
San Diego	Home Modification resource list	Online	https://sandiego.networkofcare.org/content/client/4/Home_Modification_Programs.pdf

Hospice and Palliative Care

Hospice and Palliative Care offers services and therapies to patients who are in later stages of HD and help the patient and family to improve quality of life as best as possible. The team consists of nurses, social workers, chaplains and volunteers. Palliative Care is offered through medical clinics and is associated with hospice. Hospice is covered by most health insurances; however, it does not provide 24-hour direct caregiving to patients. Please contact Social Worker for referrals in your local area.

Location	Name	Contact	Website
Nationwide	National Hospice and Palliative Care Organization	Online	https://www.nhpco.org/
Nationwide	Hospice Directory	Online 800-854-3402	http://www.hospicedirectory.org/
Nationwide	American Hospice Foundation	Online	https://americanhospice.org/
Nationwide	American Academy of Hospice and Palliative Medicine	Online	http://aahpm.org/
Nationwide	Questions to Ask Hospice Providers	Online	http://www.caregiverslibrary.org/Portals/0/ChecklistsandForms_QuestionsAboutHospiceCare.pdf
Nationwide	Ever Plans	Online	https://www.everplans.com/
Nationwide	Get Palliative Care	Online	https://getpalliativecare.org/
San Diego	Vitas Healthcare	877-655-7749	https://www.vitas.com/
Nationwide	Caring Connections	Online	https://www.nhpco.org/patients-and-caregivers/
Nationwide	Compassion and Choices	Online	https://www.compassionandchoices.org/
Nationwide	Aging with Dignity	Online	https://agingwithdignity.org/
Nationwide	Center to Advance Palliative Care	Online	https://www.capc.org/

Housing – General Resources

These resources listed will help guide you in finding the appropriate housing that will meet your loved ones needs. Additionally, see pages 34-38.

Location	Name	Contact	Website
San Diego	Senior Housing	855-513-0763	https://www.seniorliving.org/
San Diego	Housing Matters	Online	https://housingmatterssd.org/resources/
San Diego	San Diego Housing Commission	619-231-9400	https://www.sdhc.org/
San Diego	211 Resources	211	https://211sandiego.org/resources/basic-needs/housing-information/
San Diego	Housing Assistance for the Disabled	Online	https://www.needhelppayingbills.com/html/housing_assistance_for_disable.html
Nationwide	A Place For Mom	Online	https://www.aplaceformom.com/

Housing: Placement agencies

Locating facilities in your area

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

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 * <i>Locate and compare quality ratings</i>	Online	https://www.medicare.gov/care-compare/?providerType=NursingHome&redirect=true
Statewide	US News Best Nursing Homes California	800-566-2910	https://health.usnews.com/best-nursing-homes/area/ca
Statewide	California Room and Board Advisory Coalition	844-657-4748	https://www.crbac.org/
San Diego	A Place for Mom A free referral service helping families find nursing homes, assisted living, retirement communities, home care and other living options.	866-463-0605	https://www.aplaceformom.com/
Nationwide	Care Pathways	Online	http://www.carepathways.com/
Statewide	California Guide to Long Term Care	Online	http://www.nursinghome.org/how.html

Independent Living Facilities

Independent Care Facilities include senior apartments and retirement homes. Independent Living Facilities enable seniors to live among their peers, however, they must be able to care for themselves. Amenities vary from none to offering daily meals, recreational and social activities, transportation, 24-hour security, and housekeeping services. Seniors who reside in independent living communities frequently employ home care aides when additional personal care and support services are needed.

Location	Name	Contact	Website
San Diego County	Independent Living Association	858-609-7963	https://ilacalifornia.org/san-diego-county/directory/#top
San Diego	ILF, private home -Euunice Ambler <i>1)7206 Aquamarine Rd, San Diego, CA 92114</i> <i>2)306 Dolo St, San Diego, CA 92114</i>	619-888-2542	These 2 homes are clean and safe. They have housed HD residents in the past.
San Diego	Saint Paul's Manor	619-239-2097	https://www.stpaulseniors.org/services/st-pauls-manor/
Chula Vista	Saint Paul's Plaza	619-591-0600	https://www.stpaulseniors.org/services/st-pauls-plaza/

Residential Care Homes/ Board & Care

Residential Care Homes have many alternative names such as "Adult Family Homes", "Personal Care Homes", and "Board and Care Homes" to name a few. These facilities are similar to Assisted Living in the types of services offered, but what makes them different is their capacity. Residential Care Homes provide a more intimate setting with fewer residents (usually less than 10 beds). Residential Care Homes serve persons 60 and older who are unable to live alone by providing room, board, housekeeping, supervision, personal care, and assistance with basic activities of living. Home care workers, including CNAs, are sometimes hired to fill in gaps of care when more help is needed than the facility is able to provide. Its important to note that a high priority will be given to residents that are able to easily blend in with the home environment community.

Location	Name	Contact	Website
San Diego	Senior Advice San Diego	800-334-9427	https://www.senioradvice.com/care-homes/san-diego-ca
Escondido	Senior Advice Escondido	800-334-9427	https://www.senioradvice.com/care-homes/escondido-ca
San Diego	A Place For Mom	866-463-0605	https://www.aplaceformom.com/care-homes/california/san-diego
Statewide	California Registry	800-777-7575	https://www.calregistry.com/residential-care-homes-for-seniors/

Assisted Living Facilities

Assisted Living Facilities are for those who may need some assistance with daily activities but do not require 24-hour supervision and medical care. Assisted Living Facilities have staff to help with personal hygiene, dressing, eating, and walking in addition to housekeeping, laundry, and transportation services. Assisted Living facilities may offer extensive onsite amenities for seniors to participate in social and recreational programs. Some Assisted Living Facilities provide care to dementia residents. Home care aides may be hired privately on a temporary basis to provide extra care when seniors are rehabilitating from surgery or have become weaker due to illness. Home care agencies can supplement your care at the place you call "home", wherever that may be.

** Indicates the facility has HD patients

Location	Name	Contact	Website
Statewide	Assisted Living Waiver (ALW) Program Participating Facilities	Online	https://www.dhcs.ca.gov/services/ltc/Documents/List-of-RCFE-facilities.pdf
San Diego-Escondido	Oak Hill Residential Care** – not for profit, assisted living facility. They do accept Medi-Cal CHG and Assisted Living Waiver Program.	760-743-8843	http://www.oakhillresidential.org/
San Diego-Vista	Vista Gardens ** – assisted living memory care facility. They have a few Medi-Cal beds.	442-224-3142	http://vistagardensmemorycare.com/
San Diego-Poway	Cadence at Poway Gardens** - assisted living	858-674-1255	https://cadencepoway.com/

Nursing Homes

Nursing Homes provide skilled care and assistance 24 hours daily and are for those who have many care requirements and cannot live independently. Nursing Homes provide rehab care on short-term basis and long-term care for those with health care needs that other housing cannot accommodate. Alzheimer's care units may be located within Nursing Homes and are designed to provide a higher level of security and safety.

** Indicates the facility has HD patients

Location	Name	Contact	Website
San Diego-Santee	Edgemoor **Skilled Nursing Facility (SNF) (Medi-Cal)	888-724-7240	https://www.sandiegocounty.gov/hhsa/programs/bhs/inpatient_health_services_edgemoor/
San Diego-Poway	Boulder Creek Post Acute ** – SNF (Medi-Cal)	858-487-6242	https://www.senioradvice.com/providers/view/villa-monte-vista-poway-ca

Incontinence Resources

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

Location	Name	Contact	Website
Nationwide	Home Care Delivered	866-514-1274	https://www.hcd.com/incontinence/low-income/
Nationwide	Paying For Senior Care	206-462-5728	https://www.payingforseniorcare.com/homecare/supplies
Statewide	Active Life Medical Products	866-643-6118	https://activelifemed.com/medical/

In-Home Assistance

In-home help involves personal care (dressing, grooming, bathing), companionship, housekeeping, personal care, grocery shopping, etc. This service is usually provided on an hourly basis and is not covered by health insurance. Most agencies will charge around \$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
PDF	Home Care: A Family Caregiver's Guide	Publication	https://www.nextstepincare.org/uploads/File/Guides/Home_Care/Guide/Home_Care.pdf
PDF	Working with Home Health Aides	Publication	https://www.nextstepincare.org/uploads/File/Guides/Home_Care/Home_Health_Aides/Working_with_Home_Health_Aides.pdf
San Diego	Coast Care Partners	619-354-2544	https://coastcarepartners.com/
Nationwide	Right at Home	877-697-7537	https://www.rightathome.net/states/california
San Diego Nationwide	Comfort Keepers	888-609-8997	https://www.comfortkeepers.com/
Nationwide	Home Instead	800-640-3914	https://www.homeinstead.com/
San Diego	San Diego Home Caregivers	619-487-9000	https://www.sandiegohomecaregivers.com/
Statewide	IHSS – In Home Supportive Services (Medi-Cal)	916- 651-8848	https://www.cdss.ca.gov/in-home-supportive-services

Legal Assistance and Forms

Legal assistance can include advocacy, estate/special needs planning, elder/disability law, criminal, housing, health and government benefits. Also see Advanced Directives section of this resource guide. Those listed below with *** understand HD.

Location	Name	Contact	Website
Nationwide	Patient Advocate Foundation	Online	https://www.patientadvocate.org/
Nationwide	Legal Planning Guide	Online	https://www.nhpco.org/patients-and-caregivers/resources/
San Diego	HICAP Elder Law & Advocacy	858-565-1392	http://seniorlaw-sd.org/
San Diego***	Ditter Law Group	858-292-0900	https://ditterlaw.com/
San Diego***	Shannon O’Neil Jones – Estate Planning, Trusts, Guardianship, Probate, Conservatorships & Adoption	619-222-5500	http://www.weberandoneill.com/

Life Insurance

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

Location	Name	Contact	Website
Nationwide	HDSA/Genetic Information Nondiscrimination Act (GINA) info	Online	https://hdsa.org/?s=gina
Nationwide	How to buy life insurance	Online	www.nolo.com/legal-encyclopedia/how-buy-life-insurance-29827.html
Nationwide	10 questions to ask your life insurance agent	Online	www.bankrate.com/finance/insurance/10-questions-life-insurance-agent-1.aspx

Long Term Care Insurance

Long Term Care (LTC) 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	Special Needs Alliance	Online	https://www.specialneedsalliance.org/
Nationwide	Shopper's Guide to LTC insurance	Online	https://www.ltcfeds.com/long-term-care/insurance
Nationwide	Elder Law Answers	Online	www.elderlawanswers.com/long-term-care-insurance
Nationwide	Administration on Aging	Online	www.longtermcare.gov
Nationwide	New & Unexpected Ways to Fund LTC	Online	www.forbes.com/sites/jamiehopkins/2014/04/21/new-and-unexpected-ways-to-fund-long-term-care-expenses/
Nationwide	Genworth Cost Calculator	Online	www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html
Nationwide	John Hancock	Online	www.johnhancock.com/products/long-term-care.html
Nationwide	Mutual of Omaha	Online	www.mutualofomaha.com/long-term-care-insurance/

Medi-Cal

The California Medical Assistance Program is California's Medicaid program serving low-income individuals, including families, seniors, persons with disabilities, children in foster care, pregnant women, and childless adults with incomes below 138% of federal poverty level.

Location	Name	Contact	Website
Statewide	When Medi-Cal will pay for a Nursing Home, Assisted Living or Home Care	Online	https://www.nolo.com/legal-encyclopedia/when-californias-medi-cal-will-pay-nursing-home-assisted-living-home-health-care.html
Statewide	How to determine if you qualify for Medi-Cal	Online	https://www.dhcs.ca.gov/individuals
Statewide	Assisted Living Waiver Program info	Online	https://www.dhcs.ca.gov/services/ltc/Pages/AssistedLivingWaiver.aspx
Statewide	Assisted Living Waiver Program Fact Sheet	Online	https://www.dhcs.ca.gov/services/ltc/Documents/ProgramdescriptandElig2018.pdf
Statewide	Medi-Cal	Online	https://www.dhcs.ca.gov/services/medi-cal
Statewide	Cal Medi Connect San Diego	Online	https://www.chgsd.com/chg-plans/cmc
Statewide	Medi-Cal Managed Care and Mental Health Office of the Ombudsman	888-452-8609	https://www.dhcs.ca.gov/services/MH/Pages/mh-ombudsman.aspx
Statewide	Cal Medi Connect Ombudsman Services	855- 501-3077	https://www.calhospital.org/cha-news-article/cal-mediconnect-ombudsman-services-now-available
San Diego County	Medi-Cal Regulation Specialists – Kathryn Humphres	877-677-6334	http://www.needmedi-cal.com/about.asp

Medical/Safety Equipment

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

Location	Name	Contact	Website
Nationwide	Broda Seating (They make custom wheel chairs for those with HD)	844-552-7632	https://brodaseating.com/
Nationwide	In Step Mobility Products, Inc	800-558-7837	www.ustep.com/
Nationwide	Philips Lifeline- medic alert necklace	800-380-3111	www.lifelinesys.com/content/home
San Diego	Harmony Home Medical	858-560-8177	https://harmonyhomemedical.com/
Nationwide	Care Foam	877-236-2687	www.carefoam.com/
Nationwide	Guardian- Strider Walker	800-833-4000	www.rehabmart.com/product/guardian-striderwalker-14973.html
Nationwide	Patterson Medical	800-323-5547	www.pattersonmedical.com/
Nationwide	Best Priced Products- Safety Devices (helmets, elbow/knee pads, etc)	800-824-2939	www.best-priced-products.com/
Nationwide	Posey- Safety Products (beds, seating, falls)	800-521-1314	https://tidiproducts.com/
Nationwide	Gunnel, Inc (chairs)	800-551-0055	www.gunnell-inc.com/
Nationwide	Alimed (cushions, support, eating utensils, padding)	800-225-2610	www.alimed.com/
Nationwide	NOA Medical (Beds and bedding accessories)	800-663-6068	www.noamedical.com/
Nationwide	Assistech- devices for memory loss/cog impairment (i.e. electronic medication reminders and communication devices)	866-674-3549	www.assistech.com/products/Products-for-Memory-Loss/-Cognitive-Disorders.htm

Medicare

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

Location	Name	Contact	Website
Nationwide	Medicare	800-772-1213	www.medicare.gov
Statewide	California Health Advocates	916-231-5110	https://cahealthadvocates.org/
Nationwide	Extra Help Program	800-772-1213	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-for-medicare-observation-status
Nationwide	Eligibility and Premium Calculator	Online	www.medicare.gov/eligibilitypremiumcalc/
Nationwide	Medicare LINET Program for meds	Online	http://apps.humana.com/marketing/documents.asp?file=1843634

Medicare Observation Status

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

Location	Name	Contact	Website
Nationwide	Difference between Medicare statuses	Online	https://www.medicarefaq.com/faqs/medicare-inpatient-vs-outpatient-vs-under-observation/
Nationwide	Medicare Self Help Kit	Online	www.medicareadvocacy.org/self-help-packet-for-medicare-observation-status/
Nationwide	Kaiser Foundation FAQ	Online	http://tinyurl.com/mtkza34

Medication Assistance

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

Location	Name	Contact	Website
Nationwide	Needy Meds	Online	www.needymeds.org
Nationwide	Rx Assist	800-668-0637	www.rxassist.org
Nationwide	Partnership for Prescription Assistance	888-477-2669	www.pparx.org/
Nationwide	PharmacyChecker.com <i>Compare Rx prices for medication; see pharmacy ratings and shipping fees</i>	Online	https://www.pharmacychecker.com/
Nationwide	Lundbeck, Xenazine USA <i>REACH Program</i>	888-882-6013	https://www.xenazineusa.com/
Nationwide	Medicare Interactive-Formulary Tier Exception	Online	https://www.medicareinteractive.org/get-answers/medicare-denials-and-appeals/part-d-appeals/requesting-a-tiering-exception

Mental Health/Behavioral Health and Psychiatric Hospital

(Also see Counseling section). In a mental health emergency in San Diego, please call 911, ASK FOR **PERT** 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	Ca Department of Human Services	916-324-0455	https://www.calhr.ca.gov/
San Diego	NAMI (National Alliance on Mental Illness)	858-634-6580	https://www.nami.org/Find-Your-Local-NAMI/Affiliate/Details?state=CA&local=0011Q000022G8R9QAK
Nationwide	What Families Need to Know about Hospitalization	Booklet	http://tinyurl.com/l6aasxy
Nationwide	Mental Illness and Hospitalization	Online	www.mentalhealthamerica.net/is-hospitalization-necessary

Neurologist

The HDSA Center of Excellence have the most experience with HD locally. If you have Kaiser health insurance, they will not refer HD patients to the Center of Excellence.

Location	Name	Contact	Website
San Diego	HDSA Center of Excellence - UCSD Dr. Jody Corey-Bloom MD, PHD	858-249-0569	https://medschool.ucsd.edu/som/neurosciences/centers/huntingtons-disease/pages/default.aspx
San Diego	Kaiser Neurology Rita Ceponiene, MD	619-528-5000	https://healthy.kaiserpermanente.org/southern-california/doctors-locations#/search-result

Occupational Therapy

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

Location	Name	Contact	Website
Nationwide	HDSA Occupational Therapy Guide	Online	https://hdsa.org/?s=occupational+guide
Nationwide	Occupational Therapy: We are HDSA	Online	https://hdsa.org/american-occupational-therapy-association-ceus/
Nationwide	Safety in the Home from HDSA	Online	https://hdsa.org/?s=safety+in+the+home

Ombudsman

Long-Term Care Ombudsman Program is a resident-directed advocacy program which protects and improves the quality of life for residents in a variety of **long-term care** settings. Ombudsmen work to resolve problems of individual residents and to bring about changes at the local, state and nationally.

The Medi-Cal Managed Care and Mental Health Office of the Ombudsman help resolve problems from a neutral standpoint to ensure that our members receive all medically necessary covered services and information for which plans are contractually responsible.

Location	Name	Contact	Website
Statewide	Medi-Cal Managed Care and Mental Health Office of the Ombudsman	1-888-452-8609	https://www.dhcs.ca.gov/services/MH/Pages/mh-ombudsman.aspx
San Diego	Long Term Care Ombudsman	800-640-4661 858-560-2507	https://www.sandiegocounty.gov/hhsa/programs/ais/ombudsman_long_term_care/index.html

Physical Therapy

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

Location	Name	Contact	Website
San Diego	Physical Therapy for All	949-735-995	https://www.ptforall.org/home.html
Nationwide	PT locator- Move Forward	Online	www.apta.org/apta/findapt/index.aspx?navID=10737422525
Nationwide	HDSA Physical Therapy Guide	Online	https://hdsa.org/?s=physical+therapy+guide
Nationwide	HDSA; Exercise/Physical Therapy	Online	https://hdsa.org/find-help/living-well-with-hd/exercise-physical-therapy/

Respite

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

Location	Name	Contact	Website
San Diego	Arch Respite	619-685-1175	https://www.arc-sd.com/respite
San Diego	Coast Care Partners	619-354-2544	https://coastcarepartners.com/respite-well/
San Diego	Southern Caregiver Resource Center	858-268-4432	https://www.caregivercenter.org/programs-services

Senior & Disabled Adult Services

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

Location	Name	Contact	Website
San Diego County	Access To Independence	Online	http://accesstoindependence.org/get-to-know-us
Statewide	California Dept of Human Services	Online	https://www.calhr.ca.gov/
Statewide	California Dept. on Aging Community Care Program- financial eligibility	Online	https://www.aging.ca.gov/
Nationwide	Job Accommodation Network	800-526-7234	www.askjan.org/
Nationwide	211 – Is the most comprehensive of locally curated social services in the United States	Online	https://www.211.org/about-us

Social Security

Social Security is an insurance program. Workers pay into the program, typically through payroll withholding where they work. They can earn up to four credits each year.

Disability Benefits

People who can't work due to a physical or mental disability that is expected to last for a year or more—or result in death—may be eligible for Social Security disability benefits. To qualify, you generally have to meet certain earnings tests. Family members of disabled workers can also be eligible.

Survivors Benefits

The spouse and children of a deceased worker may be eligible for survivor benefits based on the worker's earnings record. That includes surviving spouses who are 60 or older, or 50 or older and disabled, provided they have not remarried. A surviving spouse who is caring for a child who is younger than 16 or is disabled may be eligible for these benefits too. For children to receive benefits, they must generally be younger than 18 or disabled. Under certain circumstances a stepchild, grandchild, step-grandchild, or adopted child may also qualify for benefits.

Location	Name	Contact	Website
Nationwide	HDSA National Resource Listing	Online	https://hdsa.org/social-security-disability/
Nationwide	Alison Bartlett, HDSA's Manager of Disability Program	Online	https://hdsa.org/find-help/healthcare-and-future-planning/ask-allison/



Speech Therapy

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

Location	Name	Contact	Website
Nationwide	Locate a Speech Therapist with American Speech-Language-Hearing Association	Online	www.asha.org/findpro/
Nationwide	Coping with Speech and Swallowing Difficulties	Online	http://hdsa.org/wp-content/uploads/2015/03/Speech-Language-Swallowing-Difficulties.pdf
Nationwide	American Speech Language Hearing Association	Online	https://www.asha.org/
International	Communication and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/communication-and-hd/
International	Swallowing and HD	Online	www.huntingtonswa.org.au/information/living-with-hd/swallowing-and-hd/

Substance Abuse/Rehab Facilities

Substance use disorder treatment programs provide an integrated system of community-based substance use disorder prevention, intervention, and treatment and recovery services

Location	Name	Contact	Website
Nationwide	National Rehabs Directory	888-373-8305	https://www.rehabs.com/treatment/rehab/
San Diego	Sharp McDonald Center	1-800-827-4277	https://www.sharp.com/hospitals/mcdonald/?utm_source=google&utm_medium=organic&utm_campaign=yext
San Diego	Sharp Mesa Vista	858-836-8434	https://www.sharp.com/hospitals/mesa-vista/?utm_source=google&utm_medium=organic&utm_campaign=yext
San Diego	San Diego Rescue Mission	619-687-3720	https://www.sdrescue.org/our-programs/
San Diego County- El Cajon	McAlister Institute for Treatment and Education	619-442-2777	McAlister Institute for Treatment and Education
San Diego	Substance Use Disorder Treatment Services	888-724-7240	https://www.sandiegocounty.gov/content/sdc/hhsa/programs/bhs/alcohol_drug_services/dmc_ods_consumer.html

Video Library

Videos resources for HD families

Name	Website
Planning and Caregiving <ul style="list-style-type: none"> • Legal and Financial Basics • Coping With Personality and Behavior Changes • Driving and Memory loss • Social Security Disability; Allison Bartlett is a disability lawyer who has several informative videos and webinars 	https://www.youtube.com/watch?v=04vtowhvrk https://www.youtube.com/watch?v=CbZ9NznUXk4&feature=emb_title https://www.youtube.com/watch?v=LnbRnnyCnA https://hdsa.org/find-help/healthcare-and-future-planning/disability-chat/
San Diego Chapter Education Day 2020 <ul style="list-style-type: none"> • Jimmy Pollard – The Huntington’s Disguise, Shannon O’Neil Jones – Estate Planning • Jennifer Hill - Mental Health and HD (from a HD-positive therapist perspective), Lindsay Zehren - Music Therapy • Kristen Rigsbee - Navigating the Assisted Living System-What you need to know before you go, Lisa Mooney LCSW – Ask The Social Worker • Dr Leora Fox – “The Latest Huntington’s Research” 	https://youtu.be/IO3dRkdOMvU https://youtu.be/SOMDsrdnKE https://www.youtube.com/watch?v=sNhlhJ_ExqA https://www.youtube.com/watch?v=Mr-512BReu4
HDSA National Convention 2020	https://hdsa.org/about-hdsa/annual-convention/2020-2/
Seth Rotberg’s <i>inspiring Ted talks about living with an HD positive test</i>	https://www.youtube.com/watch?v=505TfMVqD8
Looking to the future – Life After Testing	https://vimeo.com/428287068
HDSA Webinars: Advocacy, Care Management, Family Issues, Finance, Juvenile Onset HD and Social Issues	https://hdsa.org/living-with-hd/caregivers-corner-webinars/
Kristin Rigsbee <i>Navigating The Long Term System</i>	https://vimeo.com/showcase/6165751/video/348534839



Youth

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

Location	Name	Contact	Website
Nationwide	National Youth Alliance	Online	http://nya.hdsa.org/
Nationwide	HD Youth Programs: Social Support	Online	https://hdsa.org/find-help/community-social-support/youth-programs/
International	Huntington's Disease Youth Organization	Online	https://en.hdyo.org/
National	Talking with Kids: A Guide for Families	Publication	https://hdsa.org/healthcare-professionals-resources/resources-for-social-workers/
Nationwide	Book: Talking to Kids about HD	Publication	https://hdsa.org/?s=talking+to+kids+about+HD
Nationwide	Juvenile HD- Guide for Families	Online	https://hdsa.org/?s=Juvenile+HD-+Guide+for+Families
Nationwide	Empowering Young Adults Impacted By Rare Conditions	Online	https://ourodyssey.org/