






MOST Requested Resources:

At a Glance

Lisa Kjer-Mooney, LCSW

Support Groups – Adults:

Support Groups can be a great way to connect with other individuals in your community that are in a similar situation. There is a variety of type of support groups available for an array of situations. There are different types of groups you can consider meeting your needs.

 <p>HD In Person -- group meets at central location. Contact Lisa Mooney, Social Worker @ lkjer@hdsa.org for a recent group listing</p>	 <p>HD Video Support Groups -- www.supportgroupscentral.com/hdsa</p>	 <p>HD Social Media Groups Facebook, Twitter, etc These may NOT be professionally monitored so please use caution when seeking advice/recommendations and always discuss issues/concerns with your medical team.</p>	 <p>General Bereavement (Grief/Loss) Support offered through local Hospice agencies and is for persons grieving the death of a loved one. Contact ANY local Hospice agency in your area.</p>	 <p>General Caregiver Support, CA Caregiver Resource Centers: https://www.caregiver.org/californias-caregiver-resource-centers</p>
--	--	--	---	---

HD Support for Youth

Huntington's Disease Youth Organization (HDYO) <https://en.hdyo.org/>
 Designed for children and parents, by HD youth in collaboration with HD professionals. Contains written and video information on how to talk with kids about HD, share HD information in a kid appropriate way and where to find HD youth support.



National Youth Alliance (NYA) <https://nya.hdsa.org/>
 Part of the HDSA services, NYA offers resources for youth and adults to find professional information and support for HD youth. NYA offers youth retreats, Youth Social Workers and forum for HD youth to connect with other HD youth across the

Housing – Long Term Care

Where to start?

Placement Agencies: assist in locating housing facilities in your area. The process includes an intake and assessment to determine care needs and financial considerations. Some placement agencies are free and others may charge an hourly rate.

HD Social Worker: Lisa Mooney, LCSW, lkjer@hdsa.org to discuss your situation and needs.

Out of Home Placement Options

Residential Care Facility/Board and Care Home	Assisted Living	Skilled Nursing Facilities
<ul style="list-style-type: none"> • Small group homes with 24/7 care provided by nursing assistances, vocational nursing, in home assistance providers. Assistance includes bathing, grooming, eating, using the toilet and walking, and they also provide socialization and recreational activities. Monthly costs for these homes vary and are usually negotiable. 	<ul style="list-style-type: none"> • Offers independent studio/apartment style accommodations and offer daily supervision and assistance with house chores and/or personal care. Meals, light housekeeping and other amenities are provided. For additional costs assistance with bathing, grooming, eating or using the toilet can be provided. The monthly charge for assisted living is determined by how much care a person requires. 	<ul style="list-style-type: none"> • offer 24 hour personal and medical nursing care for persons unable to care for their own needs and safely be independent.

In Home Care Assistance:

In Home Assistance	Home Health/Hospice	In Home Support Services (IHSS)
<ul style="list-style-type: none"> • Paid privately or by long term care • Provides "custodial" care services <ul style="list-style-type: none"> • dressing, bathing, grooming, toileting, bathing, meal preparation, light housekeeping, transportation, household shopping, companionship, etc • cost is by the hour and usually has a per day or week minimum • Internet or company search for Senior Care Assistance or In Home Assistance Agencies. 	<ul style="list-style-type: none"> • Medical care that is covered by medical insurance • Must be ordered by a physician • Is only for SHORT TERM (up to 6 weeks) • Does not provide custodial care as discussed to the left • Reach out to your Primary Care Doctor or HD team for referral. 	<ul style="list-style-type: none"> • Only available to persons that have MEDI-CAL insurance coverage • This program covers in home care paid by Medi-Cal for custodial care needs as discussed under In Home assistance in this table • Is not available 24/7, limited to the number of hours authorized by Medi-Cal based on their assessment of the persons needs. • Contact your County Health Services department that manages Medi-Cal.

Legal Assistance

CA Caregiver Resource Centers

- offer free educational seminars/classes about Future Planning, Living Wills, Trusts, etc. These are usually presented by Attorney’s working in the field.
<https://www.caregiver.org/californias-caregiver-resource-centers>

Employee Assistance Programs (EAP)

- your employer may also have short term legal services/advice available to you. Contact your Human Resources department for more information.

Friend Referrals/Word of Mouth

- often you will meet other HD families at educational events, fundraisers or support groups that have utilized legal assistance in your area, if they had a positive experience you may consider contacting the resource/person they used.

Behavioral Health and Coping Resources for the Entire Family



Support Groups -- see above



HDSA

Support groups, education events, webinars, research updates, written publications.



Help4HD

Education events, support groups, radio shows, HDTV, holiday assistance programs.



Suicide Prevention Lifeline

1-800-273-8255;
<http://suicidepreventionlifeline.org/>

provides 24/7, free and confidential support for people in distress, prevention and crisis resources



Individual Counseling

- Your Health Insurance
- Employee Assistance Program through your employer.
- Telehealth/therapy
- College counseling center

Additional Resources

UC Davis HDSA Center of Excellence California Caregiver Resource Centers

AARP Caregiving