

Increasing Your Support System

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Discussion

- Why support is needed
- What support is available
 - HD specific
 - Community
- Practical ways to expand your support system
- Personal stories of those in HD Families

Why is Support Needed?

- Coping with a disease like HD can evoke a great deal of emotions/feelings, such as:
 - Fear, frustration, hopeless, helpless, overwhelmed, depressed, anxious, mad, isolated, misunderstood, alone, scared, etc
 - Sometimes the best way to cope and process these emotions is to share them, express them, and sometimes find ways to move through them.

Why is Support Needed?

- What the statistics say...
 - 40 to 70% of caregivers have clinically significant symptoms of depression, with 1/4 to 1/2 meeting diagnostic criteria for major depression. ¹
 - 22% of caregivers are exhausted when they go to bed at night and many feel they cannot handle all their caregiving responsibilities. ²
 - Financial, Emotional, Physical, Health, Family, Employment, Spiritual/Religious, Self-care, etc

¹Caregiving in the U.S., 2015, Family Caregiver Alliance, page 2 of 11 <https://www.caregiver.org/print/22290>

²Caregiver Health, Family Caregiver Alliance, page 2 of 11 <https://www.caregiver.org/print/22290>

Why is Support Needed?

- So what does that mean...as a Care Partner I'm destined to be depressed?
- Additional Research has also shown that...
 - Social Support has been shown to be associated with QOL among carers of people with neurological illness³
 - Carers are more resilient than expected in the face of increased hardship.⁴

³ Elodie J. O'Connor, Marita P. McCabe (2010), Predictors of quality of life in carers for people with a progressive neurological illness: a longitudinal study. Quality of Life Research

⁴ Elodie J. O'Connor, Marita P. McCabe (2010), Predictors of quality of life in carers for people with a progressive neurological illness: a longitudinal study. Quality of Life Research

HD Support Resources

- Medical Support Resources
 - HDSA Center of Excellence
 - Kaiser Sacramento
 - Stanford
 - UCSF
 - UC Davis
- Educational Support Resources
 - Education events
 - Locally we have 5-7 per year
 - National HDSA Convention each year (this year LA)
 - Webinars (HDSA.org)
 - Social Workers

HD Support Resources

- Educational Support Resources (cont.)
 - Online
 - UC Davis HDSA COE website
 - Patient and care partner resources, genetic testing information, research opportunities
 - HDSA
 - National Convention (in LA this year); website, webinars, online support groups, publications
 - HDYO (Huntington's Disease Youth Organization)
 - Fantastic resources for youth and parents to share with youth.
 - Help 4 HD:
 - Weekly Radio Show, website, publications, HD events around the country,

HD Support Groups

- Support Groups can be a great way to connect with others
 - In Person: 7 in Northern California
 - Video – HDSA offers for Caregivers and At-Risk persons. www.supportgroupscentral.com/hdsa
 - Social Media Groups – there are online support groups through Facebook and possibly other social media websites. These may NOT be professionally facilitated or monitored so please use caution when seeking advice or recommendations and always discuss issues/concerns with your medical team as well.

Expanding your Support System

- Participate:
 - HD Support groups, education events, and fundraisers
 - Community classes or organizations that interest you.
- Meet your neighbors
- Ask family/friends for help
- Read about others experiences
 - Lots of HD books and stories available:
 - Watching Their Dance (Local Family—can purchase downstairs)
 - Inside the O'Briens
 - Dancing with Elephants
 - The Woman Who Walked into the Sea
 - Many, many others

Expanding your Support System

- Watch Documentaries on HD:
 - HD Warriors – (Screening May 17th here in this building.)
 - Huntington's Dance
 - Alive and Well
 - My Mother's Daughter
 - The Lion's Mouth Opens
 - Twitch
 - Do You Really Want to Know
 - A Mind In Quicksand
 - Many others....

Expanding your Support System

- Identify local community resources
 - Senior Centers
 - Spiritual/Religions Organizations
 - Adult Day Healthcare
 - Counseling/Therapists
 - Traveling Groups

Personal Experiences

- Please share a little about your HD story?
- What are the ways you have expanded your support system?
 - Family, friends, neighbors, community organizations...
 - Benefits/Challenges?
- Talk about your experience with HD Support Groups
 - In person, online chat/social media groups or video
 - Benefits/Challenges?
- What is the most Positive/beneficial activity/thing which helps you cope with HD?
- Advice for our families? Recommendations?

Resource Contacts

- Lisa Mooney, HD Chapter Social Worker
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- HDSA Center of Excellence @ UC Davis
 - Webpage: <https://www.ucdmc.ucdavis.edu/huntingtons/>
- HDSA
 - Webpage: www.hdsa.org
- Help 4 HD International
 - Webpage: <http://help4hd.org/>