



# Navigating Huntington's Disease

# 2020

The following Frequently Asked Questions & Tips were received from HD patients and families. If you have specific questions about your needs please contact your HD care team and/or contact Lisa Mooney, Chapter Social Worker at 916-734-6277 or [lkjer@hdsa.org](mailto:lkjer@hdsa.org).

*I want to extend a very special thank you to all the Northern California HD families that demonstrate tremendous courage and kindness in sharing their experiences, challenges, struggles and successes for other HD families to learn from, feel supported by and inspire hope during the own HD journey. I am so honored to witness the collaboration, support and love among the Northern California HD Community.*

# Frequently Asked Questions & Tips from HD Families

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## Care Partner Needs

**When the spousal relationship changes, are there tips on how to cope with the transition from spouse to caregiver?**

Often the “nursing” or caregiving aspect of the relationship begins to take more time, thus minimizing the time needed to maintain the spousal relationship. Sadly, spouses often feel they have “lost” their spouse and may start to view their spouse differently and not as an intimate partner as the HD progresses and the care needs of the HD person increases. As the disease progresses HD persons will not contribute to the family in the same way they did before and thus the role/responsibility they had before is either lost or must be covered by someone else -- often the “well” partner. These changes will impact many areas of the relationship: connection, intimacy, communication, health and wellbeing of both individuals, finances. All these changes will ebb and flow over time and as the disease progresses. Early on you may not have much change, but as the disease progress you may experience some of these changes more intensely. A diagnosis of HD does not mean you are destined to be divorced, unhappy, isolated, depressed, or any of the other changes and challenges listed above. To cope with this change you must be 1) aware that the changes may be a result of HD and 2) adjust and make changes to keep a connection with each other and maintain a quality of life despite the changes. Some tips and recommendation for both HD person and “well” spouse is:

- Never too early to start having open and honest communication with each other. Tell each other your fears, joys. Make sure to process with somebody (partner if you can or other supportive person) your feelings as this is freeing and often releases the burden of that thought/feeling. This will become more challenging for HD persons over time, but spouse should continue to seek out other ways to communicate their honest feelings with others (i.e. Support Groups, family, friends.)
- Get control of what you can (diet, exercise, medical intervention/symptom management, routine)
- Get help with mood and behavior changes early. Your ability to manage mood and behavior will allow you to feel better and be able to manage life stressors more effectively.
- Continue to do what makes you happy: maintain positive social relationships, enjoy hobbies, do things to help foster self-esteem and sense of purpose even if your HD loved one is not able to participate or join you.
- Redefine Intimacy and Sex: intimacy does not necessarily mean sexual intercourse; finding what means LOVE to you is key: human touch can fill our human need for connection and intimacy. Things like holding hands, watching movies while sitting together, going for a walk. Sitting on a park bench, massage, bathe together, cooking together, etc. can all be good ways to maintain intimacy and connection with your spouse even as the disease progresses.
- Set realistic expectations for both yourself and as a couple: if your spouse

can't be your confidant anymore find another friend or family that provide that for you.

- Focus on the small joys and victories you may experience. Like a successful and enjoyable meal out, family gathering, etc.
- Ask for help – what responsibilities can you delegate to other family members or neighbors (transportation, shopping (delivery service), yard work, etc. to reduce your stress and have more time to care for yourself or your relationship.
- Focus on health and self-care; establish routines that include time for self-care (exercise, massages, meditation, etc.) to be able to better manage stressors.
- Expand your support system – support groups, volunteering, hobbies.
- Avoid making promises you can't keep (promise to keep them safe and comfortable vs. I promise to keep you home...)
- Be present – find the joys in the NOW, plan for future but put the energy into the NOW.
- Faith and Spirituality – don't forget or lose sight of what is important to you and your relationship and the value you offer. HD does not define you; relationships are hard to maintain and take effort. Small adjustments can be made to help you cope with the changes in your relationship.

Remember, there is NO right or wrong way in this HD journey. There is SUPPORT, you are NOT alone.

**How do we care for the Care Partners (caregivers)? Any resources or tips to help us?**

Caregiving is a process that will involve a great deal of change in family structure and roles as well as a change in what you accept as "normal" daily life. Caregiving requires a great deal of patience, strength, flexibility, creativity, and energy. You will need courage to ask for help and accept the situation you are in, along with insight and recognition of your limitations and the limitations of your loved one.

Caring for someone with HD is a long term commitment therefore it is important to remember that is not selfish to focus on your own well-being and desires. After all, if you cannot care for yourself, you will limit your ability to successfully care for your love one. Please seek medical attention if you are experiencing any prolonged physical or emotional symptom interfering with your health and/or your ability to care for your loved one. Help and support is available, you just have to ask for the assistance. Lastly, we know that caregiving is a challenging and difficult job, so make sure to reward and praise yourself for your commitment and efforts to care your HD loved one.

*Tips and Recommendations:*

- Caregiver Resources – HDSA Center of Excellence @ UC Davis has a page dedicated to Caregiver Resources that discuss topics like self-care, preparing for the future.
- HD Support Groups are a good resource to speak to others that have/are experiencing similar situations. See Community Resources for HD for listing of local in person support groups.

- On-line Video caregiver support groups are also a great resource to connect with HD caregivers this is a great place to get some advice and/or validation that you are doing everything right, caring for HD loved ones is HARD.
- Individual Therapy/Counseling – HDSA offers a FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA's free telehealth portal, visit [www.hdsa.amwell.com](http://www.hdsa.amwell.com) or download the free Amwell® app and use the codes HDSA or HD to access the Huntington's disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in your state. The session is free for families affected by HD, and no insurance is required.
- Caregiver Education or Online Recommendations:
  - AARP: written resources and recommendations to help caregivers under AARP Caregiving.
  - California Caregiver Resource Centers: located throughout California and offer classes, support groups, respite, legal assistance and other resources to assist caregivers.

## Community Resources for Assistance with HD Care Needs

### What are Respite Care and Home Health Services?

**RESPITE CARE:** Respite services can be of assistance to family care providers to give them time away from caregiving responsibilities to give them time to tend to other responsibilities or care for themselves. Respite services are often needed to give family care providers a much-needed break and prolong family care provider's ability to provide care in the home. There are various types of Respite care that may be available in your area:

- Family Caregiver Resource Centers have respite programs for eligible families that will provide a certain number of hours per month/quarter to allow family care providers to hire a caregiver to address needs, giving the family care providers time to care for themselves.
- Local Assisted Living Facilities or Alzheimer's Living Facilities may offer respite services at a cost not often covered by insurance. They usually will have an apartment like setting where a family can bring a loved one for short term (usually up to 2 weeks) for respite. This type respite care is for if family is going out of town and the patient cannot travel with them, etc. The patient in this case would stay overnight at their facility and cared for by their staff.
- Community Based Adult Services/Adult Day Health Care is a good resource to give caregivers a break during the day. Long Term Care Insurance may cover this care. The patient can often get picked up at home and will be taken to the facility for socialization, physical therapy and meals during the program. Usually is about a 6 hour program to give caregivers a break and provide services to the patient. To find a local Adult Day Health Care center in your area, please visit the California Department of Aging Website.

- In Home Assistance is available for a cost (may be covered by Long Term Care Insurance). It is usually around \$20--\$25 per hour depending on where a person lives and their care needs. Services provided are companionship and custodial care needs (eating, dressing, cooking, cleaning, bathing, etc). Medi-Cal recipients may be eligible to get this benefit through IHSS (see above). You can do an internet search for In Home Assistance agencies in your community.
- In-Home Support Services (IHSS) is a program for Medi-Cal recipients. If patients are granted IHSS hours, they may hire family members or outside caregivers to care for their needs and in doing so may offer respite to the primary caregivers.

**HOME HEALTH:**

- Home Health must be ordered by a Physician and is short term, specifically if patient just got out of hospital, rehabilitation center, etc. This is available for patients that have a skilled need where a they may benefit from: Nursing, Physical Therapy, Occupational Therapy, Speech Therapy or Social Work to aid in successful recovery at home. Home Health services are often covered by medical insurance.

**What is In Home Assistance and how is it different from Home Health?**

In-Home Care Assistance consists of companionship, housekeeping, cooking, dressing, grooming, bathing, grocery shopping, etc. This service is provided on an hourly basis and is NOT covered by most health insurances. Costs range between \$20--\$25 per hour and may have a 3-4 hour minimum. Medi-Cal patients can apply for In Home Support Services (IHSS) which provides the above services.

**The difference between Home Health and In-Home Assistance is:**

- Home Health is a SHORT TERM (typically 3-6 weeks) consisting of licensed medical professionals (RN, Physical Therapy, Occupational Therapy, Speech Therapy, Social Worker) that comes to your home to assist with safety in the home, educating about safe care practices, setting up proper use of equipment, etc. This service does not address the personal care needs of the patients (such has dressing, bathing, toileting, etc.). Home Health is covered by most insurance.
- In Home Assistance focuses on the personal care needs of the individual in need. They will assist with dressing, bathing, toileting, feeding, light housekeeping, etc. the goal of this care is to provide respite to family care providers and/or care to allow the individual to stay in the home without need for out of home placement. This service is NOT covered by most health insurances (Medi-Cal being the 1 exception—see above).

## Community Resources for HD

**Can I receive e-mail notifications about upcoming educational events and activities?**

Both the Northern California Chapter and National HDSA have e-mail notification systems to inform you of upcoming activities.

- *HDSA National:* [www.hdsa.org](http://www.hdsa.org) Click "Subscribe" banner at the bottom of the webpage and enter your contact information.

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|   | <ul style="list-style-type: none"> <li>Northern California HDSA Chapter: <a href="http://northernca.hdsa.org/">http://northernca.hdsa.org/</a> Scroll near bottom of page to the area titled Newsletter Sign Up, use the “click here to sign up “ and enter your information.</li> </ul>   |
| <p><b>Where can I get more education about HD?</b></p>                            | <p><i>Local Education Events</i></p> <p>In the Northern California area there are about 4-6 HD Education events every year. For information about upcoming local events periodically check the following Facebook or webpages:</p> <ul style="list-style-type: none"> <li>HDSA Northern California Chapter Website or Facebook page: <a href="http://northernca.hdsa.org/">http://northernca.hdsa.org/</a> or <a href="http://www.facebook.com/hdsanocal">www.facebook.com/hdsanocal</a></li> <li>HDSA Pacific Southwest Regional Facebook page: <a href="https://www.facebook.com/pages/Huntingtons-Disease-Society-of-America-HDSA-Pacific-Southwest-Region/115252895152973">https://www.facebook.com/pages/Huntingtons-Disease-Society-of-America-HDSA-Pacific-Southwest-Region/115252895152973</a></li> <li>HDSA Center of Excellence @ UC Davis Health website or Facebook page: <a href="http://www.ucdmc.ucdavis.edu/huntingtons/index.html">www.ucdmc.ucdavis.edu/huntingtons/index.html</a> OR <a href="https://www.facebook.com/UCDavisHuntingtons/">https://www.facebook.com/UCDavisHuntingtons/</a></li> </ul> <p><i>For National or Internet/Webinar based events please visit:</i></p> <ul style="list-style-type: none"> <li>Huntington’s Disease Society of America (HDSA) <a href="http://www.hdsa.org">www.hdsa.org</a></li> <li>Huntington’s Study Group (HSG) <a href="https://huntingtonstudygroup.org/education/">https://huntingtonstudygroup.org/education/</a></li> </ul> |
| <p><b>What support is available in Northern California for HD families?</b></p>   | <p>Northern California is an area rich in HD support. We have 4 HDSA Center of Excellence’s, 5 In-person support groups per month, 3-4 video groups per month, 4-6 educational events per year, 3-4 Team Hope Walks per year and other community and fundraising events. The best way to stay connected with the events in this area is to sign up for e-mail notifications @:</p> <ul style="list-style-type: none"> <li>Northern California HDSA Chapter: <a href="http://northernca.hdsa.org/">http://northernca.hdsa.org/</a> Scroll near bottom of page to the area titled Newsletter Sign Up, use the “click here to sign up “ and enter your information.</li> <li>You may also check the webpages and facebook pages listed in the previous question.</li> <li>Support Groups: please visit the HDSA Center of Excellence @ UC Davis, Northern California HDSA Chapter, HDSA Bay Area Affiliate for in-person and video groups. Currently in-person support groups are in El Cerrito, Mill Valley, Santa Rosa, Palo Alto and Sacramento. Video groups cover all Northern California and Bay Area.</li> </ul>   |
| <p><b>My HD loved one is living in another state, how can I support them?</b></p> | <p>It can sometimes be challenging to feel helpful to family that may not live near you, that said, staying in phone, text or video contact can have positive benefits for you and your family members on the other end. Often people need someone to talk to and share feelings with and they want to feel like somebody cares and people are thinking of them. If you can offer financial support to help pay for a nice out to dinner meal, movie or get households needs/groceries delivered, pay for house cleaner, yard service, etc. that can be helpful in assisting with daily responsibilities and getting some time to tend to other needs. Sometimes people need help completing forms or making phone calls so if that is something you could assist with</p>   |

that may be helpful too. In most cases being there emotionally for people is appreciated and anything you can offer that will help free up some of their time or take responsibilities off their “to-do” list is beneficial and appreciated.

**What services is a HD social worker good for?**

HD Social Workers will of course have more understanding of HD and likely to be more familiar with HD specific needs and/or resources. HD Social Workers either with HDSA Centers of Excellence or HDSA Chapters can provide a a variety of services including:

- Supportive Counseling for HD patients, families and caregivers: family care meetings, grief support, presentations/trainings about HD, problem solving, emotional support.
- Information about Community Resources and Benefits: Medi-Cal, Disability, in home assistance, Out of Home placement, Adult Day Health Care, HD support groups, etc.
- Information and Education about HD: managing HD, advance care planning, what to expect, how to talk to your children about HD, etc.
- Community Advocacy and Education: trainings and presentations to Board and Care homes, nursing facilities or other community caregivers about HD, how to care for persons with HD, etc.

I, (Lisa Mooney) is the Northern California Chapter Social Worker and UC Davis HD Social Worker and can be reached at 916-734-6277 or [lkjer@hdsa.org](mailto:lkjer@hdsa.org). Each of the other 3 local HDSA Centers of Excellence also have HD Social Workers, please see previous page for those contact numbers.

**Is there a resource for hands-on, free help in completing important forms like Power of Attorney, social security, bank, health care, etc?**

Unfortunately, I am not aware of any community agency or program that offers assistance in completing forms. That said, there are resources that may provide more information that will aid someone in completing specific forms or agencies that will assist in completing a form specific to their work. Examples:

- Social Security Disability Forms: There are local Social Security offices throughout the state. You can make an appointment with a Social Security employee to get forms, ask questions and complete your Disability forms. Please call 1-800-772-1213 to find the nearest Social Security office near you. A listing of Social Security Offices is also available by visiting [www.ssa.gov](http://www.ssa.gov).
- Financial Power of Attorney: Banks and other financial institutions may assist you in completing the Power of Attorney for Finances as needed by their institution.
- Health Care Power of Attorney: information regarding Advance Health Care Directives and how to complete can be found via the internet by doing a search for Advance Health Care Directive.

If you need assistance with completing forms or you have questions about any forms, I am available to assist with answering questions and problem solving. Please contact me directly at 916-734-6277 to discuss your specific needs.

## Financial Resources

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| <b>I heard social security added HD as a disability, what does that mean?</b>  | <p>Adult on-set Huntington’s Disease (HD) and Juvenile Huntington’s Disease (JHD) were both added to the Social Security Administration’s Compassionate Allowance List (CAL). This means applications under the Social Security Disability Income (SSDI) or Supplemental Security Income (SSI) programs will be expedited for people with a Huntington’s Disease diagnosis. Remember, having a gene positive blood test does NOT automatically qualify you for Social Security Disability. You must be diagnosed by a MD as having HD symptoms that prevent you from maintaining employment. There is no change to the application process. For more information about applying for Social Security please visit <a href="http://www.ssa.gov">www.ssa.gov</a>. For information about tips and recommendations for applying for disability under HD diagnosis, please visit: the UC Davis HDSA Center of Excellence Website – <i>How to Apply for Social Security Benefits</i> or <a href="http://HDSA.org">HDSA.org</a> for more disability information.</p>   |
| <b>When should I apply for Disability?</b>   | <p>If you were employed in California and paid into the State Disability Insurance (SDI) you can apply for State Disability Insurance, this however needs to be completed within 45 days of your last day of employment due to disability. You can find more information about <i>State Disability</i> at: <a href="https://www.edd.ca.gov/Disability/Disability_Insurance.htm">https://www.edd.ca.gov/Disability/Disability_Insurance.htm</a> State Disability is considered short term disability and will only cover up to 12 months of your disability.</p> <p><i>Social Security Disability</i> – you should apply for disability as soon as possible AFTER you have stopped working or inability to find employment or return to work force due to disability. Applying to early (before your disability is documented or causing difficulties in ability to work) will receive a denial. Please visit <a href="http://www.ssa.gov">www.ssa.gov</a> for eligibility requirements. You will need to ensure if you are applying under Huntington’s Disease that your HD care team (Neurologist) or PCP has clearly documented your symptoms, limitations and your inability to meet employment expectations.</p> |
| <b>Do you know of any outside funding sources if our family is not able to meet our obligations?</b>   | <p>If you are having difficulties meeting your financial obligations you may consider speaking with your bank or a Financial Planner as they may be able to better assist you in identifying programs or opportunities that may help you meet your specific financial obligations.</p>   |
| <b>We are having difficulties paying our mortgage, there are some programs that adjust mortgages due to hardship; are there any negatives in doing this?</b> | <p>I cannot offer any advice regarding mortgages or adjustment loans as that is not my area of expertise. However, I can recommend speaking to a professional in the Mortgage, Real Estate and/or Financial Planning business as they would be able to evaluate your specific situation and provide you with the most recent information/programs available as well as pros/cons.</p>  |

## Future Planning

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| <b>How does long term care insurance work?</b>  | Long Term Care Insurance is a supplemental insurance that is purchased like life insurance. Long Term Care Insurance can cover care expenses such as in-home assistance, Adult Day Health Care, and out of home placement; services that medical insurance does NOT cover. The amount long term care insurance will pay for these services is dependent on your policy. To learn more about long term care insurance please visit California Partnerships for Long Term Care.   |
| <b>When should I get long term care insurance, life insurance, disability insurance?</b>  | Any supplemental insurances, such as life insurance, long term care insurance or disability insurance should be secured PRIOR to any genetic testing for HD and before any symptoms begin. Most supplemental insurances will do a medical review prior to approving a policy and having a diagnosis of HD or positive genetic test will likely exclude you from getting approved. Other medical conditions may also be barriers to getting supplemental insurance policies like these as well. As earlier as financially feasible is our recommendation.  |
| <b>When should we complete an Advance Health Care Directive, Living Will or Durable Power of Attorney?</b>                                    | Completing Advance Health Care Directive, Living Will, or Durable Power of Attorney should be <i>DONE for all persons (not just those with HD) as soon as possible</i> . Advance Health Care Directive forms can be downloaded and completed in just a few minutes. Living Will or Trusts are more extensive and completed with assistance from attorney therefore can take 4-8 months to complete. The most important part of this process is to have discussions with loved ones about your health care wishes and desires BEFORE anything happens. This is an extensive topic that is difficult to thoroughly discuss in a FAQ, however, please visit HDSA Center of Excellence at UC Davis Webpage, <a href="http://HDSA.org">HDSA.org</a> , or Coalition for Compassionate Care of California.   |
| <b>Is it possible to still discuss and plan with an HD person about life and future needs as the HD progresses? What does that look like?</b> | It is hard to know what HD Persons comprehend in the later stages of the disease due to cognitive decline, speech difficulties and difficulty expressing their feelings/opinion. It may be challenging for them to express their wishes or even express their understanding especially when it comes to complex issues such as medical, financial, or long term/future needs. That said, caregivers often express, especially spouses, that they do not feel comfortable making decisions without their HD loved one at least knowing what is going on which is understandable. when sharing plans or discussing complex dilemmas/decisions with HD loved ones you may consider the following: <ul style="list-style-type: none"> <li>• <i>Set realistic expectations</i> – if your loved one is having difficulty communicating daily needs/desires, they are not going to be able to express their feelings, wishes, and desires about something more complex.</li> <li>• <i>Why do you want to share or discuss with your HD loved one?</i> If you want to share out of respect for your loved one, it may be best to share once the best decision has been made to not cause any unnecessary anxiety. Again, set up realistic expectations about the response you may get. If you are looking for validation that they appreciate the decision or even agree that may not be realistic.</li> <li>• If your loved one still wants to participate and realistically can, keep it to 1 or 2 direct questions at a time, to not overwhelm or confuse them. Make sure</li> </ul> |

to pick a time of day when the HD person is most aware and awake. In this instance, more complex issues/decisions may need to be discussed and/or decided without your HD loved one present or maybe even without their knowledge if they cannot actively understand and participate in the discussion. Again, HD person may or may not be able to effectively evaluate all the various scenarios, consequences or potential options to determine what is in their best interest. Ask anyone, HD or not, nobody WANTS to go to a nursing facility, however that is often inevitable and the best option/choice to keep your loved one safe and cared for.

- You may present what is needed to your HD loved: for example “x, y, z decisions need to be made and I am taking care of it to limit any stress/anxiety on you, but if you have questions, please let me know and I will be happy to talk with you.” This way they feel invited to participate and can make the decision for themselves to participate or not.
- Whether you discuss and plan with your HD loved one or you chose not to, you CAN continuously reassure them that you will do everything you can to support, care and love them. Most often people just want to know that you are thinking of them and doing what is in their best interest and not being secretive.
- As the disease progresses the ability for your loved one to participate in long term, future decisions will decline. It may be that it is in their best interest and your best interest to make those decisions on your own or in consultation with others that you can trust.

## Genetic Testing

**Should I encourage my at-risk adult children or family members to test?**

Testing for HD is a complex and challenging PERSONAL decision. At-risk individuals should not be forced, encouraged or discouraged from testing. Rather you are encouraged to honor the wishes of the at-risk individual and support whatever decision they have made for themselves as they will have to cope and live with the results. It is important that persons choosing to test be ready to receive the information and have necessary supports in place to process and cope with the results. Please see next question for resources and where to get more information about HD genetic testing and things to consider.

**Are there resources available to help someone decide whether or not they should test for HD?**

There are lots of places one may explore to determine if testing is right for them. First and foremost, at-risk persons should contact their nearest HDSA Center of Excellence (see the Community resources for HD for list of Northern California centers) to discuss available options, costs, things to consider before testing, etc. HDSA Centers of Excellence are experts in the area of HD genetic testing and can offer at-risk persons an objective conversation to help them determine what is best for them.

In addition, persons may wish to do some internet research. Below are some credible sites that will provide more information about HD testing, things to consider and best practices for the testing process:

- UC Davis HDSA Center of Excellence Website, Genetics tab
- Video by Genetic Counselor Mara Sifry-Platt (Kaiser and UC Davis) – 10 minutes gives overview, things to consider, etc.  
<https://www.youtube.com/watch?v=4HW5YdgM4zs>
- HDSA.org – Genetic Testing pamphlet
- Huntington’s Disease Youth Organization (HDYO) – has some great written and video resources for at-risk adults about personal testing experiences and/or testimonials from those that have chosen not to test.

## Living with HD

**Some of my family is not acknowledging my HD. How do I deal with them not understanding and thinking I’m just “lazy” or making my limitations up?**

This is a challenging situation. The lack of understanding or support you are getting from loved ones could be due to a variety of reasons (lack of education/understanding about HD in general, personal reasons –their inability to process or cope with your diagnosis or their own risk status, or for reasons you may not know about or understand yourself. That said, I would recommend:

- Encourage you loved ones to attend HD medical appointments or research visits with you. That way they can hear what the HD professionals are saying about your specific symptoms and limitations AND they can ask questions and get more educated about HD.
- Encourage loved ones to attend HD support groups, HD education events, webinars, advocacy walks so they have more exposure to others with HD and can talk with professionals, other HD families and feel more connected to the HD community in hopes that will increase their understanding of your HD journey.
- Consider attending individual or family counseling to address these concerns or issues to see if a resolution and understanding can be found.
  - Individual Therapy/Counseling – HDSA offers a FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA’s free telehealth portal, visit [www.hdsa.amwell.com](http://www.hdsa.amwell.com) or download the free Amwell® app and use the codes HDSA or HD to access the Huntington’s disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in your state. The session is free for families affected by HD, and no insurance is required.

In some cases, for reasons that may not be known, loved ones may never be able to provide you with the support and understanding you want or need. In these cases, it is best to seek support from other persons, maybe through HD community events, support groups or other social activities like (senior centers or individual/group counseling). Coping with the idea that loved ones can’t provide you with what you want, and need can be challenging and the most effective way to cope with that is to find the connection and support you need in other ways. Remember, loved ones cannot be everything to us and it takes a larger support

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| <p><b>Tips how to safely transfer to/from car in late stages of disease?</b></p>   | <p>system to get all our needs met.</p> <p>This is a great question to consult with a Physical Therapist aware of your needs or your HD loved ones needs. There are several videos available via the internet that can give you ways to safely transfer in/out of car. Please remember that it is BEST to speak with medical professionals that are familiar with your needs/loved ones needs before using advice shared via the internet.</p>  |
| <p><b>Home Safety, Accessibility and Modifications</b></p> <p><i>(additional tips/recommendations in the Medical Assessment, Equipment and Modifications section in this document)</i></p> | <p>If you plan to stay in a private home, consider exploring options for equipment or home modification like:</p> <ul style="list-style-type: none"> <li>• Bathing:             <ul style="list-style-type: none"> <li>○ when person can no longer bathe themselves or needs assistance you will need to make sure there is a bathroom in the home that 1) can handle maneuvering equipment in/out of bathroom (i.e. walker, wheelchair, shower bench/chair, toilet raiser, hand held nozzle, etc.), and 2) has enough space to allow for 1 or 2 people to be in the bathroom/shower area safely to assist with bathing needs.</li> <li>○ If bathroom cannot accommodate the needs of a disabled person you may consider remodeling bathroom for easier access (i.e. walk in/wheel in shower; installing permanent shower bench/chair, installing grab bars, handheld nozzle, removal of sliding shower doors, etc.</li> </ul> </li> <li>• Rest of Home:             <ul style="list-style-type: none"> <li>○ Is your home designed to allow for medical equipment, like walker, wheelchair, hospital bed? You will need to look at things like size of door frames, stairs within home and getting in/out of the home; width of hallways, size of rooms to allow for hospital bed, wheelchair, hooyer lift, etc. and other persons to safely been in room to assist with transfers and care needs.</li> </ul> </li> </ul> <p>For assistance with identifying way to modify your home to accommodate someone with HD or other disabilities we recommend:</p> <ul style="list-style-type: none"> <li>• Research and talk with professionals about things to consider as disease progresses.</li> <li>• Look up various options via internet or talk to other families that have cared for disabled persons in the home to find out what helped them</li> <li>• Please follow these links for some helpful resources about home modifications, home safety and things to consider:             <ul style="list-style-type: none"> <li>○ AARP:</li> <li>○ Rebuilding Together:</li> <li>○ Eldercare Locator</li> </ul> </li> </ul> |
| <p><b>How do we navigate the HD progression? Are there resources/tips to make life easier for HD person and Caregiver?</b></p>   | <p>There is not necessarily and right or wrong way to navigate HD progression, as it is different for everyone. Some recommendations include:</p> <ul style="list-style-type: none"> <li>• Seek HD specialized care for assistance with treating current symptoms and planning for what may come next. See <i>Community Resources for HD</i> section of this document for a list of HDSA Centers of Excellence in</li> </ul>  |

Northern California.

- Attend support groups as they are a great way to feel connected and less alone. You can share your feelings, get recommendations from HD families and stay up to date on HD education, treatment and research opportunities. See *Community Resources for HD* section of this document for a list of HD Support Groups in Northern California.
- Individual Therapy/Counseling – this can help you cope with the stressors of HD and other life stressors. It can be a person to share your feelings with judgement free.
- Education: learn all you can about HD disease progression:
  - UC Davis HDSA Center of Excellence has extensive resources available for free download about HD
  - HDSA Publications can be valuable resources in learning about HD and preparing for what is next.
    - Caregiver Guide for Families
    - A Physician’s Guide to the Management of HD
    - Caregiver Guide for Mid to Late Stage HD
    - Understanding Behavior in HD
    - Caregivers Guide to HD
- Consider ways to simplify life and reduce responsibilities like seeking assistance with yard work, household cleaning, transportation, grocery shopping, etc.
  - Home delivery services to reduce trips to pick up essential and frequently used items, groceries, meal kits or even cooked meals.
  - Cleaning Service
  - Meal kit service
- Consider ways to make home safer and more user friendly for HD persons to remain independent for as long as possible. Things like, Smart Home Technology which is an evolving field that can be very helpful to monitor a loved one when away from the home, or have doors open or lights turn on automatically.
  - Can help address social isolation and maintain relationships
  - Motion detection, smart lights, smart door locks,
  - voice assistance technology to manage t.v., electronics, music, phone, and thermostat. Voice assistance can also provide reminders for medication, exercise, appointments, etc.
    - Internet Search on Smart Home Caregiving Technology can provide other ideas and ways to utilize and set up smart home technology in your home.
      - HD Presentation @ 2018 National Convention discussing Smart Home Technology
      - AARP Caregiving

## Long Term Care Placement

**Is there any list of facilities that will accept HD individuals? I'm concerned for the time that may come when my loved one outlives his/her money and he/she ends up on Medi-Cal?**

In Northern California we do not currently have any long-term care facilities that specialize in HD. However, there are three different levels of out of home placement that is available throughout Northern California. The type of placement needed will be dependent on the person's care needs. All of these facilities are able to accept persons with a variety of illnesses, including HD; however, each facility has the discretion to accept or deny admission. Keep in mind that the long-term placement process can take many months (or even YEARS with Medi-Cal) and will take a great deal of persistence and patience.

Assisted Living Facilities are for individuals who are mostly independent but require some daily supervision and assistance with house chores and minor personal care. They offer rooms or apartment-style accommodations, social activities, and meals. *Health insurance does not cover placement in this type of facility.* Long Term Care Insurance may cover placement in this type of facility.

Residential Care Facilities/Board and Care Homes are small group homes (usually 3-8 residents) that provide constant supervision, meals, bathing, grooming, eating, toileting, etc. *Health insurance does not cover placement in this type of facility.* Long Term Care Insurance may cover placement in this type of facility.

Skilled Nursing Facilities (SNF) offer 24 hour personal and medical nursing care. *Long term placement (over 100 days) is NOT covered by health insurance, however, is covered by most Long Term Care Insurance policies and is covered by Medi-Cal.* If you do not have the above insurance, placement will need to be paid privately. SNF placement costs vary by the persons care needs and by where you live, however at minimum the cost would be about \$6,500 – \$10,000 per month.

To identify placement facilities in your area and for a listing of SNFs that has or has had experience with HD please refer to the *Northern California Resources* guide on the HDSA Center of Excellence at UC Davis website.

**If I am a veteran with HD who served in a war, am I eligible to reside in a VA Nursing Home?**

My understanding is VA Nursing Home placement is restricted to veterans that have a service connection of 70% or higher. You will likely have a service connection if you experienced an illness or injury as a direct result of your military service. The VA determines service connection. For specific information on the VA Benefits you may be eligible for please contact the VA nearest you or visit [www.va.gov](http://www.va.gov).

There are also Veteran Homes in California. These homes usually have multiple levels of care: independent living, assisted living and nursing home. In general the homes are designed for people to enter when they are relatively healthy and can live independently. Then as residents age and need additional care it can be offered at the same location. There is a cost associated with Veteran Homes. For more information visit the [www.cdva.ca.gov](http://www.cdva.ca.gov).

## Maintaining Health and Well Being

**What can caregivers do to help HD patients exercise/use their brains effectively?**

To my knowledge there is no specific exercise(s) that has been scientifically proven to improve brain function. HD is a neurological disorder that attacks the brain and causes damage in how it functions. The damage to the brain is not a result of not exercising or using your brain effectively, but due to the HD gene attacking the brain.

Health care professionals will always recommend a healthy and nutritious diet as well as daily exercise to increase overall health and functioning. In addition to your physical health, your emotional health can have both positive and negative impacts on your overall health; therefore, reducing stress may have a positive impact. You can reduce stress by asking others to assist you with responsibilities; relaxation activities such as yoga, deep breathing, meditation, etc; taking time to do something you enjoy, watching movies, connecting with friends/family, or pampering yourself may be beneficial in improving overall health.

**I'm having trouble coping with caring for my HD loved one, the change in mood, behaviors and increase in responsibilities is making me feel overwhelmed?**

Caring for persons with HD can be very difficult and challenging at no fault of the HD person. If an HD person is having difficulty with mood and behaviors, many of those symptoms can be effectively managed and minimized with proper medication, therefore please have your HD loved one evaluated by his/her HD care team to determine if medication is appropriate.

There may also be some environmental and/or stress management techniques that can help both you and your HD loved one. Things like exercise, deep breathing, and getting emotional support can all help people feel less alone and identify ways to cope with the difficulties.

- *HD Support Groups* (see Community Resources for HD of this document) for a list of local in person support groups. Video Support groups may also provide a benefit, please visit [www.HDSA.org](http://www.HDSA.org).
- *Individual Therapy/Counseling* – HDSA offers a FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home. You may also have individual therapy benefits directly through your medical insurance as well.

There are some *helpful written resources* to help with finding and implementing good self-care practices and coping strategies to use for yourself or to be able to better care for your HD loved one:

- UC Davis HDSA Center of Excellence – Self Care for Caregivers, Speaking to your Loved Ones MD, A Guide to Everyday living with HD
- HDSA Publications:
  - Understanding Behavior (has good tips for medications and environmental techniques to address challenging behaviors)
  - A Caregiver Guide for HD Families: (helpful tips on working with various HD care providers and resources to address all aspects of caring for HD persons)
  - Caregivers Guide to HD: (offers coping strategies, helpful tips and resources to address all aspects of caring for HD persons)

**How do we manage other health issues that come up? It is so hard to know if it is HD related or something different. My HD loved one says everything is HD and then won't go to the MD.**

This is a great question and one that we hear often, because in most HD families, HD is “blamed” for most issues – and rightly so since HD is so complex and does trigger and have a variety of symptoms that come about during the disease process. That said, HD persons are not exempt from getting or experiencing other health issues (although they should be in my opinion!). While it is important to have your HD care team to address the HD issues/symptoms, it is also important to have a Primary Care Physician (PCP)/General Practitioner that you visit at least annually or more frequently as needed for general health and well-being. PCP’s can help with seasonal cold/flu prevention and symptoms, which of course are not HD related. They can also assist with getting beneficial therapies involved (Physical Therapy, Occupational, Swallowing, Social Work, equipment, etc.) as needed for both HD or other injuries or health issues. PCPs will also do annual physicals, routine annual lab work and address any pain or lab abnormalities. Basically, it is always good to have a local PCP, close to home and familiar with you so any medical issues or abnormalities can be addressed as quickly as possible. Lots of things can be blamed on HD, but that doesn’t mean that a PCP can’t treat the issue/concern and help you feel better.

## Medical Care, Equipment and Home Modifications

**Is there any place where caregivers can find tools and ideas for helping one another? For instance, I need to know if anyone has used a suction machine at home...as swallowing becomes more difficult, I want to have one available. Is there a specific website that has a section devoted to adaptive tools that work, (i.e. beds, wheelchairs, padding, utensils, cups, shoes, etc.)?**

First, before purchasing/using any medical equipment I would strongly recommend discussing your needs with your health care team (i.e.. MD, Physical Therapist, Nurse, Speech Therapist, etc) to ensure that the equipment is appropriate and safe. For information about medical equipment:

- [HD Support Groups](#) are a good resource to speak to others that have/are experiencing similar situations. They may be willing to share techniques, equipment and/or ideas that worked well for their family.
- [On-line Video caregiver support groups](#) may also be a resource to ask questions and get feedback from others on useful tips and equipment.
- [Medical and/or HD Care Team](#): please discuss the challenges and concerns you are experiencing at home and ask what help and/or equipment might be beneficial for your needs.

*Internet Resources:*

- AARP – has online information about equipment and tips to make home caregiving safer and more efficient.
- Web searches for medical equipment, home safety modification may offer some insight as well.

*HDSA Publications:*

- Physical and Occupational Therapy – Family Guide Series
- Caregiver Guide for Mid to Late Stage Huntington’s Disease: Pages 34-69:

**What kinds of home modifications are recommended?**

Home modifications are usually recommended to make the home safer or easier to navigate as the disease progresses. Recommendations can range from removing throw rugs, minimizing stairs, installing ramps, handrails, to widening door frames, remodeling bathrooms/living space to accommodate medical equipment. The need

*(additional tips/recommendations in the Living with HD section in this document)*

for home modification is going to be based on your specific needs and situation. Attending support groups (in-person or video) is a good way to get feedback from other HD families about what worked or did not work for them. You can also do a web search on home modification recommendations that may also provide some helpful ideas or tips. As always, we encourage you to consult with your HD care team before committing to equipment or home remodel to make sure it is appropriate for your needs.

AARP *How to Make your Home Safer* has some practical tips to help make your home safe. They also have a home safety checklist that may be helpful in identifying areas in your home where safety should be improved.

**What are some of the challenges for caring for HD persons at home I should prepare for?**

*(additional tips/recommendations in the Living with HD & Maintaining Health and Well Being section in this document)*

Some of the biggest challenges will be falls HD Persons are going to fall, some can be avoided by removing tripping hazards (rugs, cords, furniture, etc.) others will just happen despite best efforts to prevent. That said, you want to clear the environment of any potential fall/tripping hazards and remove nicks, coffee tables or limited use furniture so if a fall does happen injury and damage risk is minimized.

Another challenge as the disease progresses is navigating the home with equipment or when a person to assist is needed. As mobility decreases and persons have more dependence on walker or wheelchair or on another person, things like bathing, going to bathroom, navigating down narrow hallways or in smaller rooms can be more challenging. You may want to consider looking into home modification or changing home layout to accommodate for equipment and make personal care tasks easier. See *Living with HD* section of this document for specific recommendations and things to consider.

Caring for HD loved ones at home is possible, but you will need assistance from other family, friends or hired caregivers. All household and life responsibilities continue and usually fall to the remaining adult in the home. In addition, then as the HD person needs more assistance with personal care those responsibilities also fall to the remaining adult. With the increase in needs within the home, it can feel very stressful and overwhelming. It can trigger changes in the care partner such as sadness/depression, anxiety, irritability, stress, decline in health, and changes in physical abilities, etc. The best way to prevent the negative impact of caregiving is to establish a strong support system of help and good self-care practices to help manage and cope with the stressors that come with life and caregiving. See Maintaining Health and Well Being section or Care Partner Needs for additional recommendations.

## Research, Clinical Trials & Studies

**Where can I find information regarding HD clinical trials and studies?**

If you would like to stay informed about the latest research opportunities, findings and scientific research as it relates to HD, please visit the sites below.

*Internet resources:*

- [www.hdbuzz.net](http://www.hdbuzz.net)
- [www.hdtrials.org](http://www.hdtrials.org)

- [www.huntington-study-group.org](http://www.huntington-study-group.org)
- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- [www.hdsa.org](http://www.hdsa.org)

*To find out what trials/studies are available locally and to identify if you are eligible please call:*

- UC Davis HDSA Center of Excellence (916) 734-3541
- UC San Francisco Memory & Aging Center (415) 476-2909
- Stanford University (650) 724-8278

## Social Support Resources and Recommendations

**How to maintain friend support system? (prevent losing friends) What can we ask friends to do to keep connected and involved, but not burdened?**

In most cases as we age our lives become smaller and smaller. Meaning our circle of friends gets smaller and more intimate (which may be good), our interests change, our desire or willingness to explore the world outside of our comfort zone becomes less and less and eventually we may not want to leave our homes at all. This is OKAY, but it is important to know that you are NOT alone and who you can call or what support is available if you need and want it. Human connection is an important part of health and wellbeing just as alone time and self-care is also important. The goal is to find a balance between the two so you can be supported with whatever your needs are at that time. Maintaining social support, friendships and connections with others can be challenging when you have HD and/or are caring for someone with HD. Often times I hear HD families stating, “we are just so busy getting through the day, next thing we realize months have gone by before we’ve had time to even talk to others.” It is important to maintain social connections outside of your family for social and emotional health. Social Support can consist of: family, friends, neighbors, church, co-workers, other HD families, etc. It is also important to recognize some relationships will ebb and flow and some relationships may end despite your best efforts to remain connected. Keep in mind that support through your HD journey is available and you may need to explore relationships outside of your current support system. That said here are some tips and recommendations to stay connected with others:

- Participate in support groups for HD and/or caregivers to build social supports of others that are living with HD as well.
- ASK for help and assistance when needed and ACCEPT help when offered
  - You may feel that asking for help may “burden” others or it may admit you can’t handle everything yourself. Nobody can care for a loved one without help from family, friends, community, or health care professionals.
  - Reaching out for help when you need it is a sign of personal strength.
  - Family/friends/neighbors often want to help but are unsure of what is needed or most helpful.
    - Prepare a list of ways others can help
      - Assist with transportation take to/from appointments

- Household tasks: walking the dog, mowing the lawn, putting out the trash, preparing meals
- Assist with completing and/or mailing benefit applications or forms
- Running errands
- Keeping HD person company while you care for yourself
- Take HD person for walk, out to movies, meal, or other enjoyable activity.
- Ask friends to keep inviting your family to social gatherings, activities stating you would like to participate when you can.
- Consider the person’s special abilities and interests:
  - maybe they are avid walkers and would be willing to take HD person or caregiver for a walk for exercise and connection.
  - If you need help with preparing meals, ask a friend that enjoys cooking, etc.
- Resist asking the same person repeatedly
- Make a list of things that need doing and be specific and direct with your requests:
  - “I want to go to church on Sunday; would you be available to keep Lisa company from 8:00 to noon?”

Family, friends or other social support persons may also be hesitant to maintain connections due to limited understanding or fear about not knowing what HD is and how to maintain connections.

- Encourage loved ones to attend HD support groups, HD education events, webinars, advocacy walks so they have more exposure to others with HD and can talk with professionals, other HD families and feel more connected to the HD community in hopes that will increase their understanding of your HD journey.

**What can a support group do for me?**

Support Groups can be a great way to connect with other individuals in your community that are in a similar situation. Support groups can offer emotional support, advice about community-based resources as well as guidance from other group members about many of HD’s most challenging situations.

*HD Support Groups -- Adults*

- In Person –see *Community Resources for HD* in earlier in this document for a listing of local HD Support Groups in Northern California
- Video – these are great way to connect with others across the country also impacted by HD.
- Social Media – there are many social media support groups through Facebook and other social websites. These may NOT be professionally

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|   | <p>facilitated or monitored so please use caution when seeking advice or recommendations and always discuss issues/concerns with your medical team as well.</p> <p><i>HD Support for Youth &amp; Young Adults</i></p> <ul style="list-style-type: none"> <li>• Huntington’s Disease Youth Organization (HDYO) is a great resources for children and parents looking for information on how to talk with kids about HD, share HD information in a kid appropriate way and has youth support forum where kids, teens and young adults can ask questions to peers, this forum is professionally monitored.</li> </ul> <p><i>Support Groups (Non HD specific)</i></p> <ul style="list-style-type: none"> <li>• Caregiver Support: these are persons caring for an aging or disabled adult. California Caregivers Resource Centers</li> <li>• Bereavement (Grief/Loss): offered through local Hospice agencies and is for persons grieving the death of a loved one. Often have adult and youth groups.</li> <li>• Other medical conditions (diabetes, cancer, Alzheimer’s, Anxiety, Depression, etc) – similar to HD specific support groups, these groups would be focus around the specific disease.</li> </ul>       |
| <p><b>I am retiring from work and will miss the social interaction, what resources can you recommend?</b></p>                               | <p>To increase and/or maintain social interaction you may want to consider:</p> <ul style="list-style-type: none"> <li>• Volunteering for a cause that is of interest to you.</li> <li>• Participating in an HD Support Group.</li> <li>• Plan and schedule frequent gatherings with friends/family/neighbors/co-workers.</li> <li>• Local Senior Centers offer a variety of activities, gatherings for persons 65 years or older.</li> <li>• Join a local church group.</li> <li>• Many local coffee shops, libraries, community centers will have postings of the social activities/events happening in the community.</li> </ul>   |
| <p><b>Who/Where can I go for moral support when family members are not supportive or just don’t understand my perspective or grief?</b></p> | <p>Unfortunately, we cannot control the support, understanding or care we receive from our family/friends. It is important to remember that in every relationship there are limits to what others can give or may be willing to provide (even though we may expect more.) We all have our varying perspectives, approaches, own baggage, feelings and grief we may be experiencing and thus unable to provide what others need from us. That said, if your family and friends are not able, unwilling or just not understanding for any reason, it may be best to find others that have experiences or struggles like you. Often, we can feel more supported and connected with others that are dealing and coping with exactly what we are and likely have similar perspectives and needs. For example, grieving is different for spouses, parents, children, extended family, and friends. Even grieving among males and females can be different and will often experience challenges in supporting one another in moving through the grief.</p> <p>If your family/friends express a willingness to learn more about HD in hopes of better understanding you and your situation, encourage them to attend HD</p> |

educational events, HD advocacy events and HD support groups.

*For everybody:*

- Northern California IN-PERSON support groups
- Individual Therapy/Counseling – HDSA offers a FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home.
- Talk to your HDSA Center of Excellence or Chapter Social Worker or HD Clinic Coordinator:
  - Lisa Mooney, Chapter Social Worker 916-734-6277 or [lkjer@hdsa.org](mailto:lkjer@hdsa.org)
  - Northern California HDSA Center of Excellences:
    - Kaiser Sacramento: 916-614-4869 & 916-614-4786
    - Stanford: 650-723-6060
    - UC Davis: 916-734-6277
    - UC San Francisco: 415-476-2904

*For Caregivers, At-risk persons or Gene expanded (no symptoms):*

- HDSA Video Support Groups

I hope you find/found this document beneficial. If you have a question, concern or need additional assistance please contact Lisa Mooney, Social Worker at 916-734-6277 or [lkjer@hdsa.org](mailto:lkjer@hdsa.org). In addition, if you identify an error or outdated information, please feel free to bring this to my attention so it can be corrected and updated as appropriate.