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Welcome to the Huntington's Disease Society of America (HDSA) Center of Excellence at UC Davis Health

We are so happy to be part of your HD care team and your HD journey. We are here to assist the whole family in coping and living with HD.

Clinic Contacts

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Please do not hesitate to reach out or ask questions when you have them.

Sincerely,

UC Davis HDSA Center of Excellence TEAM





Resource Contacts

Question	Person to Contact	Phone/E-mail	Website
How do I get my prescription refilled?	Neurology Clinic	916-734-3588	Activated UC Davis MyChart account
How do I schedule my next appointment?	Neurology Clinic	916-734-3588	
I was looking for information/resources about HD, where do I find information? find information?	Lisa Mooney, LCSW Social Worker	916-938-3576 Imooney@ucdavis.edu	
How do I get a message to my doctor?	Neurology Clinic	916-734-3588	Activated UC Davis MyChart account
I'm interested in HD Research, where do I find more information?	Fernando Rodriguez, Kristen Phillips, Raj Tsutsui, Research Coordinators	(916) 734-7706 farodri@ucdavis.edu	0 7
Who can I call to verify that my insurance is accepted at UC Davis?	Health Consumer Resources Center	800-282-3284	
How do I find more information about Genetic Testing for HD?	Lisa Mooney, LCSW	916-938-3567 lmooney@ucdavis.edu	

HDSA CENTER OF EXCELLENCE AT UC DAVIS 3160 Folsom Blvd, Suite 2100, Sacramento, CA 95816 (916) 938-3576 (HD HELPLINE)

https://health.ucdavis.edu/huntingtons/





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DISCLOSURE

This HD Resource Guide is provided by the HDSA Center of Excellence at UC Davis Health.

The information provided in this guide is for informational use only. We encourage all patients and families to consult with their primary care provider, neurologist or other healthcare provider with any questions or concerns regarding Huntington's Disease (HD).

Each person is affected by HD differently and therefore consulting with your healthcare team will provide information more specific to your unique situation and health care needs.



Introduction to HD

Vicki Wheelock, MD

HD is a neuropsychiatric illness that can be very complex and challenging in many aspects. The impact of HD extends beyond the person experiencing HD symptoms to also family, friends, and your social & community support. This is a general overview of HD symptoms, care and treatment. More detailed information on specific symptoms can be found at the HDSA Center of Excellence UC Davis website or by contacting Lisa Mooney, HD Social Worker.



Huntington's Disease Society of America (HDSA) Center of Excellence at UC Davis Health

There are 55 HDSA Centers of Excellence across the country. Each center is staffed with HD knowledgeable and experienced professionals to assist HD patients and families. The HDSA Centers of Excellence provide an multidisciplinary approach to Huntington's disease care and research.

Our Mission

- To provide excellent, comprehensive & compassionate care and outreach to HD families.
- To provide expert education about HD to families, researchers and health care providers
- To advance HD research

Our Story

- We were established in 2001.
- Providers include:
 - Movement Disorder Neurologists
 - Psychiatrist
 - Genetic Counselor
 - Social Worker
 - Physical Therapist
 - Research Coordinators



https://health.ucdavis.edu/huntingtons/

Symptomatic Persons

50,000 in US

Found in All Cultures Worldwide

HD gene discovered in 1993.

At -Risk

150,000 - 200,000

Each offspring of an affected parent has 50% chance to inherit

Symptom On-Set

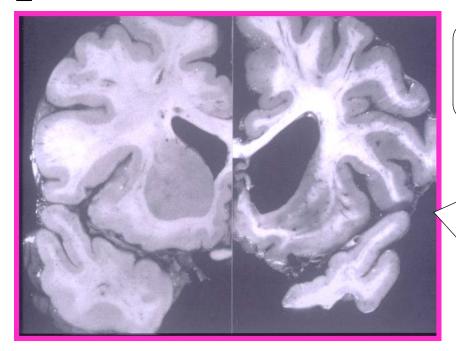
Late 30's to mid 40's

Cognitive & mood changes may occur earlier

Is diagnosed when motor symptoms are observed and confirmed via blood test



HD Symptoms



"Normal" Brain degradation

HD Brain degradation

Motor Symptoms: Balance Problems; Slow Eye Movements; Slowness of Movement; Trouble Swallowing, Decreased Fine Motor Tasks; Fidgety,

Cognitive & Behavioral Symptoms:

Impulsivity; decreased creativity; episodic anger or irritability; depression, anxiety, OCD, psychosis, decreased ability to organize, concentrate and prioritize; decreased multitasking.

Stages of HD – HD is often "staged" for purposes of identifying research eligibility. The stage of HD a person is at is based on their functional abilities to work, manage finances, perform activities of daily living (dressing, bathing, grooming, eating), ability to complete household tasks and where the person is living (at home, facility, with other family).

Stage 0

• Presymptomatic

Stage I

- Slightly lower performance at work
- mostly independent at home with minor assistance with managing finances, chores or other responsibilities

Stage II

- May still work, however experiencing more challenges, decline in performance
- mostly independent at home may need assistance with organizing and assistance with complex tasks (paying bills, completing forms, scheduling appointments)

Stage III

 No longer able to work, needs assistance with managing finances, organizing and prioritizing home activities and personal care

Stage IV

Needs 24 hour supervision and major assistance with care

Stage V

• Likely bed bound, full time nursing care required



When to get diagnosed?



HD person is ready

- Emotionally -- being diagnosed with HD can trigger lots of emotions, stress, etc.
- Very personal and someones needs and feelings should be considered.



Benefits of Early Diagnosis

- help establish baseline and build working relationship with your HD team.
- Can assist with smoother HD course in future (i.e.) catch symptoms early to minimize negative impact on life.
- Learn about HD resources, interventions, and education that CAN help manage the illness.
- Get involved in research opportunities (if interested)
- relieve uncertainty, anxiety to determine IF symptoms are or are not HD.
- allow persons to be proactive in decisions about work, higher education, future planning (financial and Advance Care Planning)



Where to be seen

- HDSA Center of Excellence -- health centers that meet criteria as experienced, knowledable and having an interdisciplinary team approcah to care and treament of HD. Please see HDSA.org for a current list of HDSA Centers of Excellence's.
- Local Neurologist -- a local neurologist may not have a great deal of experience or knowledge in working with HD, however they may be a good place to start getting care more local to home or to assist with getting referral to HDSA Center of Excellence.
- Primary Care Physician (PCP) -- every person should maintain contact with a local PCP for health related needs. Can be a place to get referral to HDSA Center of Excellence for HD care when ready.

NOT alone! There is care and support available.

Remember, you are



After Diagnosis

Establish with a HD care team/provider for ongoing follow up and symptom management.

bo Future (Advance Care anning Planning, Living Will, Advance Directive, etc.

Disability or Work Accomodations

Connect with HD por community/resources

Support Groups

Education Opportunities

Research



General HD Care Considerations









Promote Brain Health

- What is good for your heart is good for the brain
- •Regular schedules for day time, sleep, and exercise.
- •AVOID brain toxins (ie. tobacco, alcohol, recreational drugs).

Manage Mood/Cognitive Symptoms

- •SupportGroups, counseling for coping
- Medication
- Neuropsychological testing to assess abilities for work/home.
- Minimize stress & anxiety
- •allow extra time for

Managing Chorea

- Physcial Therapy
- •Regular Exercise
- Medication
- Safety equipment as needed (helmets, walker, wheelchair, etc)

When to consider MEDICATION

- when the symptom bothers the patient.
- when symptom

 interfering with daily
 life (work,
 relationships, ability to
 enjoy life, etc)
- frequent falls, dropping things or repetitive injuries
- weight loss



BRIEF overview of HD symptoms: In general we consider HD symptoms to impact 3 areas: Physical/Motor abilities, Cognitive/Thinking abilities and Mood/Behavior Changes.

Prevalence of Mood Symptoms in HD

Symptom	Percent of people with HD may experience this
Depression	40-80%
Anxiety	30-40%
Obsessions/compulsions	10-20%
Irritability	Common
Apathy	20%
Episodic Anger	Common
Psychosis	5%

Cognitive Impairment

This type of cognitive change is called Frontal-Executive Disorder and includes difficulty with:

Prioritizing, Organizing, Decision making, Creativity, Multi-tasking and ability to start and end activities.



Motor Symptoms

Chorea

- Involuntary Movements that are often sudden, irregular and purposeless.
- Nearly all adults with HD experience chorea

slowness of movement

• muscle or joint rigidty

Dystonia

• repetitive, abnormal patterns of muscle contractions frequently associated with a twisting quality.

Poor Balance/Fall Risk

• HD persons are at increased fall risk

TREATMENT of Movement Symptoms

- Exercise
- Physical Therapy
- Medications to minimize chorea



Differential HD motor features with age:

- Rigidity
- Slowness
- Muscle spasms

Juvenile On-Set



- Chorea
- Rigid-dystonic (about 10%)

Adult On-Set



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Cognitive Symptoms



Cognitive/Thinking Changes

- Often some of the first changes or symptoms.
- May impact work performance or ability to manage responsibilities



Work or Home Accomodations

- Consistent routine & schedule
- Simplify enviornment/tasks
- limit stress



TREATMENT of Cognitive Symptoms

- Routine/Schedule
- Limiting stress
- Reduce responsibilities/complex tasks that take more brain effort (organization, planning, memory, etc)



Mood/Behavior Symptoms

- Often some of the first changes or symptoms.
- May impact relationships, communication.
- Often are very distressing for the entire family.
- Depression, Anxiety, Irritability, Anger, Suicial thoughts, apathy, etc.
- Common mood symptoms (depression, anxiety, irritability, anger) can respond well to medication.
- Counseling -- support groups, therapy, etc
- Education
- Implementing effective coping strategies (communication, home safety measures, etc)

Emotional/Mood Symptoms



Treatment of Mood/Behavioral Symptoms





Other HD Symptoms

Speech Changes

- Rhythm, intonation & coordination of speech may change
- May speak in soft/low tone
- Mumbled or Slurred speech with difficulty of others understanding
- Less talking, delay in response (due to slow processing)
- TREATMENT: Speech therapist, education and cognitive strategies.

Seizures

- Mostly common in Juvenile Onset HD
- Associated with a high number of CAG repeats.
- TREATMENT -- Neurology workup: EEG, imaging and medication can be effective in managing.

Weigt Loss

- More common in mid to late stage HD
- Causes: Increased metabolic demands from chorea; cognitive impairment; mood symptoms/apathy; swallow difficulties; poor absorbtion of food.
- TREATMENT: Work with your medical provider to determine best approach --Increase calorie intake, medication to stimulate appetite; eating schedule/reminders; Dietician referral; feeding tube placement

Sleep Issues

- Difficulty falling or staying asleep
- exessive daytime sleepiness
- reversal of sleep/wake cycles
- TREATMENT: regular sleep schedule, sleep hygience, limit t.v., electronic and caffeine before bed, address motor issues, medication (as prescribed/recommended by doctor)
- AVOID sedative drugs as they can worsen thinking and behavior.

Bladder & Bowel Changes

- Some may develop increased frequency of urination OR difficulty emptying bladder.
- Constipation or loose stool.
- Cause: may not be identified, however medications can contribute to these GI changes. Speak with MD before STOPPING any medication.
- TREATMENT: bathroom schedule/routine, attention to food/water intake, referral to urology or uro gynecology specialist.

Pain

- HD person may not recognize or report pain they feel. May express with increase agitation, sudden changes in behavior (groaning, screaming, etc)
- Causes: hunger, severe chorea, dystonia, injuries from falls, pressure sores, urinary retention or constipation.
- Expected in late stage HD
- TREATMENT: optimize nutritional support, medication for motor symptoms, fall prevention, protective padding, repositioning in bed/chair, pain reliving medication



What now? Getting an HD diagnosis is devastating, however some have found there are opportunities that bring some positivity in their HD journey.



Research Participation

while currently there is no known cure or treatment to delay symtoms, participating in research can help scientists learn more about HD and hopefully find a meaningful treatment.



Health Living

Heart healty diet
Exercise
Avoid toxins (smoking, alcohol
& drugs)



Education and Social Support

Education yourself on strategies to manage symptoms.

Talk with other families, medical professional and community organizations to help support you and challenges that may arise.



For more information about treatment for specific symptoms or strategies to manage mood, cognitive changes or physical changes please visit the HDSA Center of Excellence at UC Davis website OR contact Lisa Mooney, HD social worker (lmooney@ucdavis.edu) for additional resources. You may also search for HDSA, Help 4 HD for additional written or video information.



Telehealth Medical Visits, Therapy and Support Groups: What to expect?

Lisa Mooney, LCSW

Since 2020 many of us have been experiencing changes in how we get medical care, therapy and support from our friends, family and communities. Although there is nothing that can replace human contact, telehealth CAN be another way to stay connected, get support AND get medical care despite physical distance.



BENEFITS:

Medical assessment, therapy and social support from the comfort of your own home.

Reduce time and money spent:

- to travel to office, gas
- Often telehealth has lower co-pays or cost

HD person may be able to more actively participate as they aren't tired from travel, can hear better, stay more focused, and are in a comfortable environment (i.e. home!).



How to Join/What to expect

Medical Appointments

- Each health system will use their branded and privacy protected system. For UC Davis Health we use MyChart application.
- The application is downloaded to a Smartphone or Tablet and accessed via log in and password.
- ✓ At the time of the visit, log in and start video visit. Your device will access the video and microphone.
- Your doctor will log in after you have.
- ✓ Video Appointments can be very effective. Many physical exams can be adapted to be conducted at home so the doctor can monitor changes, improvements or progression.
- It may be best to have another person present during the visit so they can hold the device if you are asked to perform an assessment task.

Support: Therapy or Support Groups

Each therapist/support group will be run through their preferred video platform (Zoom, WebEx, Skype, Facetime, etc.)

- Support will be conducted similar to in-person meetings as far as opportunities to share and discuss what is on your mind.
- ✓ Video does allow one to see and feel the emotions of others, which helps with emotional connection and validation.
- Participants find that the support received via video is just as beneficial as the support inperson.
- ✓ There can be technology glitches (slow) connections, paused/frozen screens, sound cutting in and out, however many times these can be resolved with small fixes. (See next page)



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VIDEO Etiquette (Things to consider)

All participants are encouraged to activate their video as that allows others to see your facial expressions and better connect with you and understand what you are expressing.

Be open to new technology! We can help walk you through how to get connected, turn on video, etc.

In group meetings everybody should have an opportunity to speak without interruption. Hosts attempt to manage/limit overtalking or side conversations but, if you are having trouble saying what you wish, signal the facilitator with raising your hand via video

Be aware of your background noise. Please MUTE yourself when you are not talking so others can hear.

If in a support group meeting -- what is said in group stays in the group. Please do NOT share any information that is not your own outside of the group. We all want to be responsible for the privacy and confidentiality of each other.

All professional health care providers are mandated reporters, while most everything is keep confidential any expressed concerns regarding suicidal thoughts/plans/attempts, danger to others, and/or abuse/neglect we do

For security issues, please do NOT post video links to social media. This helps limit "video bombers" that just want to interrupt meetings.

Please be willing to actively participate if you join video meetings when appropriate.

Please do NOT take photos, screen shots, video, or recordings of telehealth meetings (including support groups) as we need to all protect the privacy of each other.

For more information

have to report.

HDSA.org

HDSA Center of Excellence @ UC Davis Help4HD

AARP Caregiving

Contact your Medical Provider



Medication Assistance

Lisa Kjer-Mooney, LCSW

Medication Assistance

Costco, Sam's Club, Target and Wal-Mart have discounted supplies of generic medication; \$4 for 30-day supply or \$10 for 90-day supply. You do not need to be a member of Costco or Sam's Club to utilize the pharmacy. If you have having difficulty paying to costs of your medication you may discuss getting on a generic version and/or other options with your healthcare team. Additional medication assistance may be available through the numerous pharmaceutical companies. Contact the pharmaceutical company manufacturing your prescribed medications for additional assistance. The organizations listed below may also offer medication payment assistance and discounted medication programs.

City	Name	Contact Information	Website
Nationwide	Needy Meds		Website offers Patient Assistance with medications, discount cards and free clinics. Please visit the website for information about eligibility and prescriptions covered. www.needymeds.org
Nationwide	WebMDRx		Website offers medication search option to find local pharmacies that offer your medication at a discounted cost. The search option will list the local pharmacies that offer the medication and what your cost will be. http://www.webmd.com/rx
Nationwide	Partnership for Prescription Assistance	888-477-2669	Website offers Medication Assistance please visit the website for eligibility and prescriptions covered. www.pparx.org
Nationwide	Rx Assist		Patient assistance program center. www.rxassist.org
Nationwide	National Organization for Rare Disorders		https://rarediseases.org/ Click the Patient and Families tab, then Help to Access Medication, Patient Assistance Programs. Programs will have time frames for accepting applications, therefore it is good to check back often for programs that may become available as

Help and support is available check out:

HDSA.org HDSA Center of Excellence Help4HD

Caregiver Resource Centers AARP Caregiving



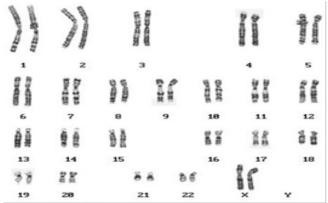


HD Genetics:

Mara Sifry, LCGC

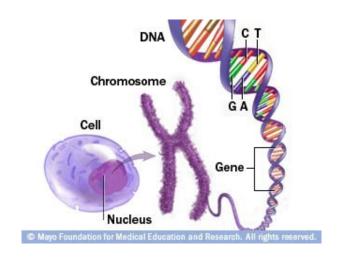
Genetics 101

Our bodies are made of cells and in each cell we carry our genetic material in the nucleus. This genetic material is the "recipe" or "blueprint" about how to make each of us. Our DNA contains all of our genes and these genes make proteins that create and determine everything about our bodies, from the chemicals that help us digest our food, to our hair color, skin color, and whether or not we will get HD in our lifetime. The DNA is packaged into structures called chromosomes that we can see under the microscope.

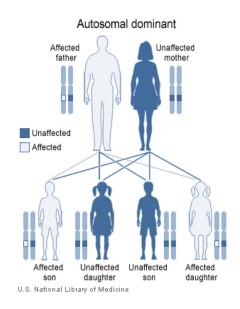


We know that the gene which causes HD is on chromosome 4 and the gene for HD makes a protein called "huntingtin." Huntington's disease is dominantly inherited which means that it takes only one abnormal copy of the HD gene to cause the disease.

A person with HD has a 50% risk of passing on this condition to each of their children. This doesn't mean that if a person with HD has 4 children, then 2 will inherit the condition and 2 won't. The 50% risk is for each child. So in this example all 4 children could inherit the gene, or 3, or 2, or 1, or none. It's like flipping a coin each time a person with HD has a child. Males and females have the same 50% risk of inheriting the condition from a parent who has HD.



We all have 46 chromosomes which come in pairs; one of each pair comes from each parent. This means that 23 chromosomes are from the mother, and 23 chromosomes are from the father.

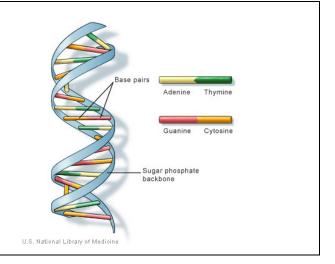




What is the genetic change in HD?

The HD gene is on chromosome 4.

Remember that genes are made up of DNA. DNA is a twisted double helix. You can imagine this molecule as a twisted ladder. The DNA is made up of a sugar phosphate backbone (the sides of the ladder) and then bases that hold the 2 sides together (the rungs of the ladder). These bases have names (Adenine, Thymine, Guanine, Cytosine). The HD gene contains a series of CAG repeats (Cytosine- Adenine-Guanine). We all have CAG repeats but people with HD have more copies of this CAG repeat in one copy of their huntington genes.



What the CAG Numbers mean:

Normal Range

- 26 or fewer CAG repeats
- Not at risk for developing HD
- Not at risk for passing to chidren

Intermediate Range

- 27-35 CAG repeats
- Not at risk of developing symptoms of HD
- considered unstable so that future generations could be at risk

Reduce Penetrance Range

- 36-39 CAG repeats
- may or may not develop symptoms of HD.
- considered unstable so that future generations could be at risk

Full Penetrance Range

- 40+ CAG repeats
- will develop HD symptoms during natural lifespan
- considered unstable and 50/50 chance of passing 40+ to children
- 60+ CAG repeats is considered Juvenile On-Set HD.

An individual's number of CAG repeats is determined at conception and we wouldn't expect it to change over time.

Paternal Inheritance: While all genders can have or pass on HD, there's an interesting phenomenon that occurs in HD where the gender of the parent you inherit an HD expansion from can impact the age of onset of HD symptoms. If you inherit the HD causing gene from your father the number of the CAG repeats MAY increase whereas if you inherit it from your mother, the number usually remains stable. This is important since we know that the number of these CAG repeats plays a role in the age of onset. In general, the higher the number of CAG repeats, the earlier the onset of symptoms although there are other genetic and nongenetic variables that can play a role in the onset and severity of symptoms.

Types of Genetic Testing for persons 18 and over:



PREDICTIVE TESTING

This testing is completed IF:

you don't have any symptoms of HD,

you are at risk for HD, AND

you want to know your HD gene status.

Testing can be an emotional process and you may want to consider some important issues before engaging in predictive testing.

RESOURCE: 10 minute video that explores the basic information about predictive testing: https://www.youtube.com/watch?v=4HW5YdgM4zs



CONFIRMATORY TESTING

This testing completed IF:

you have symptoms of HD

This includes a comprehensive medical evaluation

your diagnosis and care plan will be discussed

blood test may be drawn at this visit to confirm the diagnosis, and the results will be shared at your follow-up appointment.

This can be an emotional process even when you are expecting abnormal results. Your HD professionals can help support and guide you through this process.



Testing Children under age 18

At this time the HDSA and the National Society of Genetic Counselors, in conjunction with researchers and clinicians experienced in caring for HD families, do not recommend testing of persons under 18, unless they have symptoms of the condition that require medical treatment.

If a child is suspected of experiencing symptoms of HD (Juvenile Onset Huntington's Disease (JHD), we strongly encourage you to contact your HDSA Center of Excellence for a medical evaluation to determine if testing is appropriate.

Many families have shared that they want to KNOW if their children carry the gene so they can prepare & plan for their future, while we certainly understand that desire as a parent we are ethically bound to think of the child's right to decide (autonomy) when they are adults themselves. HD is considered an Adult Onset Disease and we know that most adults at risk for HD choose not to have predictive HD DNA testing. We would never test an adult without their consent and making sure their desire to test is NOT influenced or coerced by others. Therefore, the current perspective is that children, once they are of adult age, should have the option of testing or not testing for HD.

Genetic Testing in Pregnancy



Prenatal Testing

can be done on an unborn fetus to determine if it is carring the HD gene expansion

This can be a very complex and emotional process so we encourage you to review the issues and procedure with a professional who is knowledgeable in HD.

CVS (Chorionic Villus Sampling) is done typically between 11-13 weeks of pregnancy. A piece of the developing placenta is removed either through a woman's cervix or abdomen using a catheter or needle. This tissue is 99% genetically identical to the fetus so DNA testing can be done for HD status and a result given. CVS carries a risk for miscarriage that can vary slightly from center to center but is usually in the range of 1/500.

Amniocentesis is typically performed between 15-20 weeks of pregnancy. Amniotic fluid that surrounds the baby is removed from the uterus using a thin needle. This fluid contains cells from the baby that can be isolated, grown in the lab, and tested for HD status. Again, amniocentesis carries a risk for miscarriage that can vary slightly from center to center but is usually in the range of 1/500-1/900



Pre-implantation diagnosis (PGD):

This is a way to test an embryo before it's implanted in a woman's uterus

Using IVF (In Vitro Fertilization) techniques, the egg and sperm are combined outside the woman's body. Once the embryo reaches a certain level of development it can be tested to see if it carries the HD gene expansion. Only embryos that are unaffected with HD are implanted in the woman's uterus. PGD can be done in a way that doesn't disclose the at risk parent's status if unknown.

For more information on PGD please check out HDFreeWithPGD and HelpCureHD

To have kids or NOT to have kids:

This is not an easy decision to make and then adding HD into the equation adds some additional questions or concerns. There is NO right or wrong decision, only what is right for you and your partner.

We encourage you to communicate with your partner about desires or concerns about having children and exploring your options together. Please reach out to a genetic counselor or HDSA Center of Excellence for additional discussion and support. All the choices have pros, cons and feelings that you must explore to decide what is best for YOU.

Reproduction Choices:

Natural conception IVF/PGD Prenatal Diagnosis Egg/Sperm Donor Surrogate Adoption Not have children

What is a Genetic Counselor and what do they do?

Genetic counselors

are medical professionals trained in the biology of genetic conditions and counseling.

Their role is to discuss the science and symptoms of genetic conditions with families. They discuss options, outcomes, and risk/benefits in a non-directive, non-judgmental, and supportive approach so YOU can make your own choice about testing, starting a family, etc.



Genetic counseling

is a supportive process where a person or family chooses to talk about genetic information and its impact on the individual and future generations.

The DNA Blood test for HD itself is a straightforward laboratory process, but the implications and emotional aftermath of the results are not as straightforward. HD is RARE and testing can be complex. The emotional burden of results can be very impactful on a person's life and future.

How do I decide to test?

Choosing to test is a PERSONAL choice. A HD genetic counselor, family, trusted friends, or clergy can help you explore all the complexities, concerns, or issues specific to you and your situation. However, the choice to test is ultimately yours alone as it is your genetic information.

There are NO Right or Wrong Answers and there are many reasons people choose to test or not test.

SOME (not all) reasons to test:	SOME (not all) reasons to NOT test:
Feeling "stuck" in the uncertainty and unknown; alleviate anxiety	no current treatment to slow progression or cure the disease
Planning for your future (relationships, children, education/career, etc)	Not emotionally prepared for the testing process or results
For future generations (for example, my adult children who are starting families)	Rather have HOPE that I don't have it. Prefer to live life and cope with things as they come.
I'm experiencing symptoms	Privacy, confidentiality or discrimination concerns

https://health.ucdavis.edu/huntingtons/

What happens in a genetic counseling session?

HD Family History

- •referred to as a pedigree/family tree
- •who in the family has HD, how old were they when they started having symptoms, and at age of diagnosis?

What is your life experience with HD?

- •how long have you known about HD risk?
- •have you seen or cared for someone with HD symptoms at different stages of the disease?

Why test NOW?

- Are you testing for yourself and not feeling pressured by others to do so?
- •Is this a good time for you to get this genetic information and process and COPE effectively with it?
- Are there any other major life stressors going on at the same time you are seeking this information? (For example, death of loved one, divorce, pregnancy, or other major life changes)

How would the results change your life?

- •what would you do differently if gene positive or if gene negative?
- Potential impact on you current or future relationships, education/career goals, having children, setting life priorities, etc)

How does your family FEEL about you testing?

- •Are they supportive or against you testing?
- Are you sharing your desire to test with them?

Privacy & Discrimination Issues

- •Insurance & Employment Discrimination is a major concern for many people considering predictive testing for HD.
- •Some laws in place for protection include:
- Health Insurance Portability and Accountability Act of 1996 (HIPAA). HIPAA doesn't allow group health insurance providers to create any rule of eligibility for a person or their dependents that discriminates against that person based on any health factor, which includes genetic information.
- Genetic Information Non-discrimination Act of 2008 (GINA) provides some security against employment and medical insurance discrimination. GINA does not yet cover life, disability, or long term care insurance, which often concerns people in families with HD. Once a person actually has signs or symptoms of the disease GINA does not appply. GINA doesn't apply to the military, the Veterans Administration, or the Indian Health Service.
- •State of California: Laws and Regulations California Health and Safety Code Section 124975-124996; State of California: Department of Managed Health Care Knox-Keene Health Care Service Plan Act of 1975; California Insurance Code
- RESOURCES: Genome.gov; Genetic Home Reference-Overview of genetic discrimination; National Institute of Health Office of Legislative Policy and Analysis and Council for Responsible Genetics A non-profit, non-governmental organization that fosters public debate about the social, ethical and environmental implications of genetic technologies.

Where to go from here?

The diagnosis of HD in an individual or family member can have an immediate or eventual impact on a person's perceptions of themselves, day to day life, and their future goals or plans. Making these adjustments is different for everyone but here at the UC Davis HDSA Center of Excellence we are committed to helping you in this important aspect of your life-bringing hope, meaning, and purpose to your life with HD. We remain available to you at any time. Please do not hesitate to contact us if you have questions or would like to discuss these issues further.



GINA & You

UNDERSTANDING GINA, THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008



Learn More!

Visit our web resource, which includes answers to common questions about GINA with examples of how the law applies, more information on the exceptions to GINA, how GINA works, and where to go if you are concerned genetic discrimination has happened to you.

http://www.GINAHelp.org

What is GINA?

The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects people from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information.

What is genetic information?

Genetic information helps you know and understand health conditions that run in your family, as well as your risk for developing certain health conditions, or having a child with certain conditions.

Why is genetic information important to me?

This information can help you make healthy lifestyle choices and important life and medical decisions. With GINA's protections, you can feel more comfortable talking about family health history with your family and healthcare providers. You may choose to use genetic testing and other services to learn about health risks without fear of genetic discrimination.

What are GINA's protections in health insurance?

It is against the law for health insurers to request, require, or use genetic information to make decisions about:

- Your eligibility for health insurance
- Your health insurance premium, contribution amounts, or terms of coverage

Sometimes health insurers need genetic information to make decisions about paying for certain tests or treatments. It is legal for them to ask for this information. However, once they have it they cannot use it to discriminate against you in the ways described above.



This means it is illegal for your health insurer to use family health history and genetic test results as a reason to deny you health insurance, or decide how much you pay for your health insurance.



IMPORTANT DEFINITIONS

Family Member: First, second, third and fourthdegree relatives

Genetic Test: The analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes

- Examples of tests covered by GINA: hereditary cancers (BRCA1/BRCA2); carrier screening (cystic fibrosis); genetic classification of tumors (to help determine treatment)
- Examples of tests not covered by GINA: Routine tests such as blood counts and cholesterol levels

Genetic Services: The receipt of genetic testing, genetic counseling, genetic education, or participation in a research study

This fact sheet was created by Genetic Alliance, the Genetics and Public Policy Center at Johns Hopkins University, and the National Coalition for Health Professional Education in Genetics, through funding by The Pew Charitable Trusts. May 2010

What are GINA's protections in employment?

It is against the law for employers to use genetic information to:

- Make decisions about hiring, firing, promotion, or pay
- Limit, segregate, classify, or otherwise mistreat an employee

It is also illegal for an employer to request, require, or purchase genetic information.

This means it is illegal for your employer to use family health history and genetic test results in making decisions about your employment.

What does GINA not cover?

INSURANCE:

Current Health Status: GINA does not prevent health insurers from making decisions about eligibility, coverage or premiums based on a person's current symptoms or diagnosis of a disease or health condition. This is true even if the condition is a genetic disease or was diagnosed in part by a genetic test. The March 2010 Health Reform law will help individuals, including those with diagnosed conditions, get access to insurance coverage for healthcare.

Other Types of Insurance: GINA does not apply to life, disability, and long-term-care insurance.

Some Federal Health Services and Systems: The health insurance protections of GINA do not apply to:

- Members of the US military who receive their care through Tricare
- Veterans who receive their care through the Veterans Administration
- The Indian Health Service
- Federal Employees enrolled in the Federal Employee Health Benefits Plan These groups have policies in place that provide protections similar to GINA.

EMPLOYMENT:

Small Employers: GINA does not apply to employers with fewer than 15 employees. **US Military and Federal Employees:** GINA's employment protections do not apply, however an Executive Order protects federal employees from genetic discrimination in employment, and the military has its own policies in place that may protect against genetic discrimination.

Additional resources:

A Guide to the Genetic Information Nondiscrimination Act

http://www.geneticfairness.org/ginaresource.html

GINA Resources from the Genetics and Public Policy Center at Johns Hopkins University http://www.dnapolicy.org/gina/

National Human Genome Research Institute, Genetic Discrimination Fact Sheet http://www.genome.gov/10002328









Genetic Testing Program

Mara Sifry, LCGC Lisa Mooney, LCSW

Genetic testing for the Huntington's Disease (HD) gene expansion became possible in 1993. The UC Davis HDSA Center of Excellence follows the guidelines for genetic testing recommended by HDSA, the US Huntington's Disease Testing Group, and the National Society of Genetic Counselors. Genetic testing is a process and is more than just finding out the results of a blood test. There are many issues at stake – financial, emotional, and social issues that involve not only the person seeking testing but other family members as well. Prior to giving a blood sample, a person seeking testing needs the opportunity to examine these issues thoroughly with people experienced in genetic testing.

PREDICTIVE TESTING



This testing is completed IF:

the person has no symptoms of HD,

is at-risk for HD,

AND wants to know their gene status.

Testing can be an emotional process and many aspects should be considered before engaging in predictive testing.

RESOURCE: 11 minute video that explores the basic information about predictive testing: https://www.youtube.com/watch?v=4HW5YdgM4zs



PRENATAL TESTING

Testing for an:

unborn fetus to determine if it is has inherited the HD gene expansion. This can be a very complex and emotional process so we encourage you to discuss the procedure, issues, and other things to consider with a medical professional knowledgeable about HD.





This testing completed IF:

symptoms of HD are suspected,

includes a comprehensive medical evaluation and exam

will discuss diagnosis and develop a plan of care for you.

blood test may be drawn at this visit to confirm the diagnosis, and the results will be shared at your follow-up appointment.

This is often an emotional process. The HD Professionals can help guide you through and provide support and you maneuver through the process.



Things to consider **BEFORE** testing:

Your Feelings/Needs

You will likely experience an array of emotions, which is NORMAL and COMMON when considering testing for something that will change your life.

Common feelings: sadness, depression, anxiety, anger, fear, overwhelm, frustration, urgency, guilt, regret, confusion, etc

The Impact on Your Life

Consider your age, insurance needs, work/school status, costs, emotional preparedness, timing of testing, & how testing may impact your life

Take time to evaluate if this is the RIGHT time for you to start this process.

Consider obtaining disability, long term care and life insurance as results may hinder ability for coverage after testing

Resources

11 minute video that explores the basic information about predictive testing: https://www.youtube.com/watch?v=4HW5YdgM4zs

Talk with family, friends, mentors, or other at-risk persons to get why they did or did not test at this time? HDSA, HDYO, HD Social Worker



Predictive Testing Process:

Phone Consultation & Scheduling

- Discuss process & get general information, HD family history, experience, concerns, etc
- Insurance info discussed
- Question and answers
- Schedule first visit
- Watch video before first in person visit

Visit 1 Initial Assessment

Meet & participate in assessments from HD Team:

 Genetic Counselor, Social Worker or Mental Health Professional & Neurologist

Assessments include:

- A family history
- medical history
- support system
- coping & mental health history
- physical/neurological examination
- provide resources & recommendations for support & coping during this process.
- Informed consent obtained
- blood drawn is at the end of this visit.
- This visit will last 3+/- hours.

Visit 2 Results Disclosure

- Test results provided
- Discussion of what results mean for you
- Time to process and ask questions IF you
 have them
- Follow up options and recommendations
- This visit will last 1+/- hour.
- Encourage you to free the entire day you get results. Whether your test result is positive or negative, it will certainly be emotional. Our experience has shown us that it is good to have unencumbered time to process the information.

Anonymous testing OR testing using insurance and/or legal name

	Anonymous Testing	Testing using Name and/or Insurance
Medical Documentation	 Legal name, address, phone number, date of birth is collected and stored in writing for the HD team. Information is stored electronically using alpha-numeric code that we assign, birthdate and address. Medical assessment and counseling session notes, and test results will be stored in the electronic medical records under your assigned unique alphanumeric code. 	 Legal name, birthdate, SSN, address, phone number, insurance provider Medical assessment and counseling session notes, and test results will be stored in the electronic medical records under your name Insurance provider (if used) will have access to this information
Process	1 telephone consult2 medical visits	 1 telephone consult May require referral from Primary Care Doctor for insurance authorization 2 medical visits
Time Commitment	 Depending on the team schedule, holidays and your schedule, on average we can schedule people 2-4 weeks from the date of the phone consultation You may always postpone or wait longer to get your test results 	 Again, dependent on team schedule, holidays, your schedule AND lab processing, we can schedule Visit 2 no earlier than 4 weeks after visit 1 You may always postpone or wait longer to get your test results.
Costs	 \$1200 (currently - please call for current cost as they can change) includes counseling, medical assessment & blood test Cost is broken down by Visit 1 and Visit 2 so full cost of each visit is due AT DATE of SERVICE. (So its about \$600 for visit 1 and \$600 for visit 2) 	 \$1200 same as anonymous program, if paying privately (w/out insurance) Insurance costs would be based upon your insurance provider. You will be responsible for any co-pays, premiums or services NOT covered by your insurance provider.
Recommendations	Bring a companion (friend/family) to each medical visit for additional support both in the assessments, as well as for results disclosure appointment.	 Bring a companion (friend/family) to each medical visit for additional support both in the assessments, as well as for results disclosure appointment.
Privacy/Confidentiality	 It's important to note that even though we take every precaution to de-identify you through this process, we can't personally guarantee that a breach of health records would never occur. No health system can ever make that claim. Health Information Portability and Accountability Act (HIPPA): http://www.hhs.gov/hipaa/for-professionals/privacy/ 	 It's important to note that even though we take every precaution to de-identify you through this process, we can't personally guarantee that a breach of health records would never occur. No health system can ever make that claim. Health Information Portability and Accountability Act (HIPPA) and by

https://health.ucdavis.edu/huntingtons/

	Anonymous Testing	Testing using Name and/or Insurance
Things to consider:	Anonymous Testing Genetic Information Non-Disclosure Act (GINA) GINA: http://www.hhs.gov/hipaa/for-professionals/privacy/ We do have the written file that connects your name, DOB to your electronic record for the purpose of: contact you to schedule your visit(s) If you need access to the information at some future date Required to pay privately as we CANNOT bill to third party payers. Test results will list ONLY your unique alpha-numeric code as the "name", therefore, in the event you test positive and for future HD care may require a test under your legal name. For example for social security or supplemental insurance you would NOT be able to submit this test as proof of disease or no disease as your legal name is not listed. In some cases, depending on need you can request a formal letter from UC Davis HDSA Center of Excellence	Testing using Name and/or Insurance the Genetic Information Non- Disclosure Act (GINA). HIPAA: http://www.hhs.gov/hipaa/for- professionals/privacy/ GINA: http://www.hhs.gov/hipaa/for- professionals/privacy/ If insurance is billed for a predictive test, then the insurance carrier as well as any future insurance carriers would be privy to the information of the test results.
	to link your identity to the alpha- numerical code.	
Testing Delays	On RARE occasion it is necessary to delay the testing process, IF a significant issue with mood, emotional stability, lack of support or an unsafe social situation is identified. However, this is a discussion not an "order" between you and our team to postpone testing until the issue(s) can be addressed and resolved. The team will make recommendations for follow up and indications to resume the testing process.	

Tel: 916-938-3576

Interpreting Results

The gene is known as the IT15, HTT, or huntingtin gene.

The abnormal HD gene contains an expanded and unstable DNA segment, which is composed of the genetic code message, "CAG" repeated a number of times in a row.

The repeating CAG fragment is longer on the HD causing gene than on the normal gene and may change in length when it is passed to offspring.

Worldwide experience suggests the following interpretations for the results of HD genetic testing:

CAG Repeat and Interpretation

- •26 & Below -- Normal
- •27 35 Normal, but potentially unstable
- •36-39 Abnormal, variable penetrance; unstable
- •40 & Above, abnormal, fully penetrant, unstable

Gene Negative

26 or less is normal. In this range, the size of the CAG repeat segment also appears to be stable.

Will NOT get HD or pass to future generations

Gene Positive/Expanded

40 CAG or greater are associated with the development of HD symptoms at some time during a normal life span.

Each child would have 50/50 chance of inheriting the gene expansion

Finding out you carry the gene expansion does not indicate when you will get the disease.

There are many factors that modify the onset and severity of symptoms.

The "Gray" area:

27-35 CAG are called Intermediate

Considered normal, but potentially unstable.

This has implications for future generations, and is best discussed with a HD genetic counselor.

The "Gray" area:

36-39 CAG are called reduced penetrance

Considered unstable, and cannot be predicted with certainty if HD symptoms will develop. Within this range, some people have been found to have classic symptoms of HD, while others have lived to be very old without developing the symptoms of HD.

This has implications for future generations and is best discussed with a HD genetic counselor



Our Team

Dr. Wheelock

- Neurologist specializing in HD
- Director of the UC Davis HDSA Center of Excellence

Dr. Duffy

 Neurologist specializing in HD

Mara Sifry

- Licensed Genetic Counselor
- HD experience and knowledge

Lisa Mooney

- Social Woker
- HD experience and knowledge

For additional information about genetic testing, or to schedule an appointment, please call the UC Davis HDSA Center of Excellence at (916) 938-3576



Frequently Asked Questions

Can someone else get my results?	Results are never disclosed to a third party
Can I get my results over the phone?	No, results are provided in-person or via video.
Can I do this process over video?	 Maybe – please discuss your needs and concerns directly with the HD team. When possible and appropriate we will do our best to accommodate your needs. Those testing anonymously, must have their blood draw at a UC Davis lab.
How much does the anonymous test cost?	· ·
How much does the anonymous test cost?	decision unless you want to. Our team does not reach out to at-risk persons unless they have contacted us first. \$1200 total
	consultation, you are NOT obligated to inform us of your
	If you have not scheduled, yet did have the phone
	IF you have scheduled an appointment and do not wish to proceed, please call the HD team to cancel.
process, what do I do?	process at any time.
If I change my mind and don't want to continue the	Testing is a personal decision and you can STOP the
	weeks to process the specimen and schedule you for your results visit.
	diagnostics laboratory for processing. It takes several
How is the blood test processed?	The DNA blood sample is drawn in the clinical laboratory at UC Davis and sent to a specialized molecular
I know about HD, can I skip the counseling and just get the blood test?	 3. Test using insurance or private pay, but test under legal name While we are sensitive to the feeling of urgency and we know it takes courage to start this process, our testing process follows the best practices guidelines for HD genetic testing that have been identified as important for the overall experience and support of the person requesting testing. Most people find the process helpful and learn things they hadn't considered prior to beginning the testing process. Multiple visits allow you to gather information you need to make an informed decision about testing. This process allows you to get to 'know' our team, so when results are reviewed, it is from providers who are familiar with you and your story.
What are my testing options?	 Not test – only about 10% of those at-risk choose to test Anonymous Test

https://health.ucdavis.edu/huntingtons/

Do I have to have a companion?	 This is a highly emotional process, that those wanting to test can often underestimate how they may feel during the process, therefore we strongly encourage you to identify a companion (such as a spouse, relative or trusted friend) to accompany you through the testing process. By having a companion physically present during the counseling and evaluation sessions, they hear the same information and can gain insight into the testing experience. It helps them understand what you are going through and increases their ability to be supportive both during the testing process and after. We do NOT recommend bringing children (of any age to this process as they have a vested interest in the outcome) thus may not be able to be present for your needs. In the same vein we don't recommend bringing untested siblings because again they have their own gene status to process and may NOT be able to be present for you and your needs during the process.
Who can I call for support during this process?	 YOU are always welcome to reach out to our HD team at any time for support, coping, questions or needs. Lisa Mooney, HD Social Worker @ 916-734-6277 or e-mail lmooney@ucdavis.edu Other resources are: Support groups HD social workers HDSA.org HDYO Help4HD Faith-based support Mental Health Provider through Employer Assistance Program or Private Pay



Additional Resources

UC Davis HDSA Center of Excellence HDSA.org HDYO HD Support Groups HD Social Worker



A. Sasha Duffy, D.O.

HDSA Center of Excellence at UC Davis

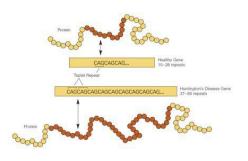


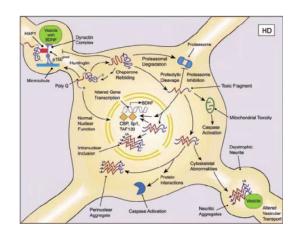


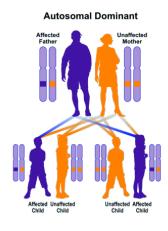
- Genetically inherited neuropsychiatric degenerative disease
- Caused by abnormal CAG expansion of the HD gene leading to a mutated huntingtin protein which causes cellular disturbances and dysfunction

50/50 chance of inheriting the gene from an affected

parent







- Symptom onset before the age of 20
- CAG repeats of > 50
- Fewer than 10% of people with HD have JHD
- Only 1-2% of people with HD have childhood onset before the age of 20 cas

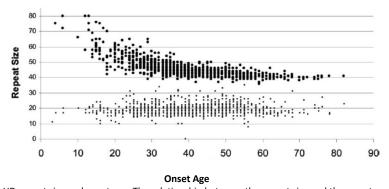


FIG. 3 HD repeat size and onset age. The relationship between the repeat size and the age at onset is presented. Person with repeats of 60 or larger commonly have very young onset, before the age of 20, and among these larte repeats there is a clear relationship between repeat size and onset age. For persons with 55 repeats or fewer, the relationship between repeat size and onset age is much weaker and the repeat size is not predictive of onset age.



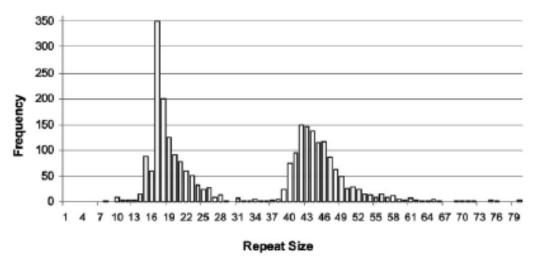


FIG. 2. Normal and expanded HD repeat sizes. The distribution of repeats for Huntington's disease may be divided into four categories. Repeats of 26 or fewer are normal. Repeats between 27 and 35 are rare and are not associated with expression of the disease, but occasionally fathers with repeats in this range will transmit a repeat to descendants that is expanded to the rant of expression of the illness. Repeats between 36 and 39 are associated with reduced penetrance whereby some individuals will develop HD and others will not. Repeats of 40 or larger are associated with the expression of HD. Personas carrying repeats in this range will develop HD, assuming they do not die of other causes before onset.

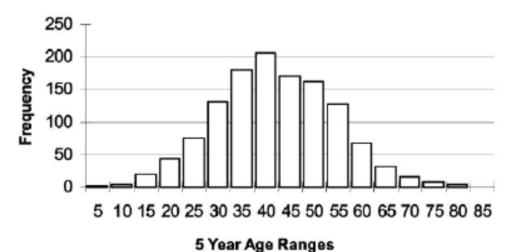
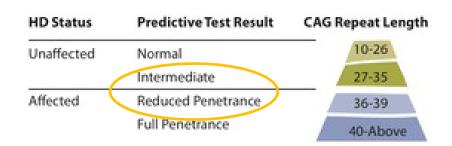


FIG. 1. Huntington's disease onset ages. The age at onset distribution in Huntington's disease is very broad and may vary from as young as three or four years to as old as 85. Onset presented here represents initial signs of motor impairment.

How do we get from 40 to 60?

- Mutable normal allele (27-35) and reduced penetrance
- "Mutable" gene is unstable and may undergo anticipation in that it may increase from one generation from the next
- Maternal transmission: +/- 2
- Paternal transmission: -2 to + 20 or more
- Paternal cases for most JHD cases (case reports from maternal inheritance)

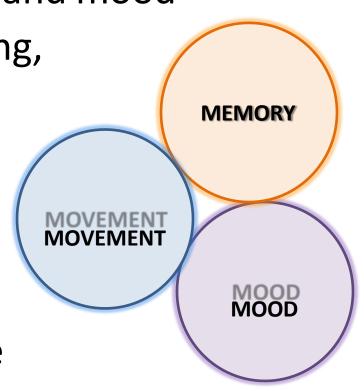


Affects memory, movement and mood

 Leading to changes in thinking, difficulties with movements and psychiatric and behavioral disturbances

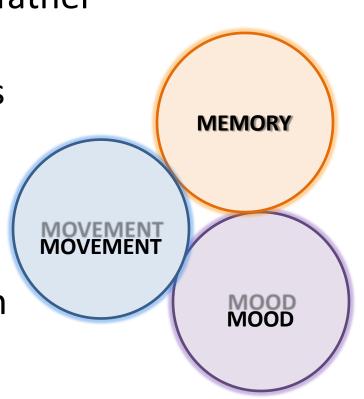
 Different from typical adult-onset HD, particularly a child under 10 years of age

Unique challenges



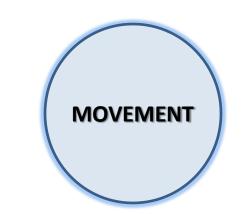
Typical Initial Symptoms of JHD

- + family history, usually in the father
- Stiffness in the legs
- Clumsiness in the arm and legs
- Decline in cognitive function
- Changes in behavior
- Seizures
- Changes in oral motor function
- Chorea in adolescent
- Behavioral disturbances





- Decline in cognitive function (thinking and reasoning)
- Initially subtle following by progression
- May appear distracted, easily be overwhelmed and/or having difficulty completing tasks
- Loss of skills previously gain (milestones) and difficulty learning new skills
- Decline in school performance
- Attention and concentration difficulties
- Problems with multitasking and decision making



- Worsening of motor skills
- Changes in speech, riding a bicycle, or throwing a ball
- Rigidity or stiffness
- Dystonia (abnormal tightness and posturing)
- Difficulty walking
- Clumsiness
- Poor oral control with drooling and difficulty swallowing
- Chorea is rare but can be seen in adolescent onset



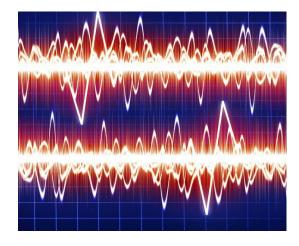
- Psychiatric and behavioral changes
- Depression: sadness, tearful, feeling hopeless, changes in sleep, appetite, energy, and overall performance
- Attention difficulties or hyperactivity
- Hypersexuality
- Aggressiveness, impulsivity, explosive behavior
- Obsessive thinking



- Effect of disease on the brain verses psychological stress of the disease
- Behaviors can be unpredictable and difficult to manage (disease verses normal changes and urges of being a teenager)
- Can lead to substance abuse (drugs or alcohol)
- Causes disruptions in family or social life

Seizures

- Can be the presenting symptom
- About 25% of children with JHD
- May be any type and differ in severity
- Babies and children can have seizures due to many other causes not related to JHD



Young Adult HD

- The young adult with features of JHD and HD
- Not everyone fits perfectly into JHD and adult-onset HD
- Special attention to an individuals' presentation and particular needs
- You can be a part of both JHD and HD



Challenges in diagnosing JHD

- Many symptoms found in other conditions
 - What else could it be?
- + HD genetic testing does not necessarily mean that the symptoms are due to JHD
- Complicated family history
 - Parent not affected yet
 - Early death of a parent (before they were affected)
 - Misdiagnosis or lack of diagnosis in affected parent
 - Non-paternity
 - adoption

Evaluation for possible JHD

- Talk to your health care provider
- Seek referral or reach out to a HD Center
- What to expect:
 - Medical and neurological history
 - Family history
 - Developmental history
 - Neurological exam
 - Discussion about impression and plan
 - Do not be afraid to ask questions
 - A diagnosis of JHD takes time
 - Routine follow-up



Genetic testing?

- If the history and examination are strongly suggestive of HD, then may proceed with confirmatory genetic testing
- If symptoms are not typical or exam is not clear, then genetic testing should not necessarily be pursued at that time
- GOAL: make an appropriate and timely diagnosis while avoiding the potential risks of testing a child inappropriately or prematurely



Your Medical Team

- HD COE: Neurologist, Psychiatrist, Social Worker, Genetic Counselor, Therapist, Research Coordinator
- Therapy: Physical, occupational and speech
- Dietician
- Primary care physician
- Dental care



HDSA Center of Excellence at UC Davis

JP Roberson Foundation
Charles and Margaret Pue Foundation

Center Of Excellence

OUR MISSION:

- To provide excellent, comprehensive and compassionate care and outreach to families
- To provide expert education to families, researchers and health care providers
- To advance Huntington's Disease research

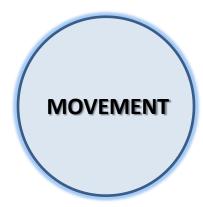


Your Medical Care

- Each person has their own individual course with medical care tailored to their needs
- Treatment focuses on
 - Education
 - Movement disorders
 - Cognitive disorders
 - Behavioral and Psychiatric issues
 - Seizures
 - Psychosocial dynamics

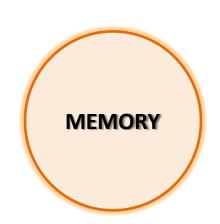
Movement Disorder Treatment

- Early intervention
- Safety devices and equipment assessment
- Physical therapy and range of motion exercises
- Safety measures and fall prevention
- Rigidity
 - Sinemet, Amantadine, Botulinum toxin therapy
- Spasticity and dystonia
 - Baclofen, Tizanidine, Clonazepam
- Chorea
 - Tetrabenazine (Xenazine)
 - Neuroleptics: Zyprexa, Risperdal, Abilify, Haldol, etc.



Cognitive Impairment Management

- Provide a stable and predictable environment
- Create daily schedule
- Minimize distractions and noise
- Simplify tasks and decisions
- Re-orientation
- Creative reminders
- Modifications at school (Individual Education Plan)



Behavioral and Psychiatric Management

- Effect of disease on the brain verses psychological stress of the disease
- Depression: sadness, tearful, feeling hopeless, changes in sleep, appetite, energy, and overall performance

Anti-depressants (SSRI, SNRI, TCA, other): Zoloft,
 Celexa, Effexor, Wellbutrin, Remeron, etc.

Behavioral and Psychiatric Management

- Behaviors can be unpredictable and difficult to manage (disease verses normal changes and urges of being a teenager)
- Aggressiveness, impulsivity, explosive behavior
 - Behavioral and environmental modification, safety plan
 - Antipsychotics, mood stabilizers or anti-anxiety Rx
- Obsessive thinking
 - Reassurance and redirection
 - Anti-depressants/ SSRI's



Behavior Management: Sexuality

- JHD verses adolescent/teenager(s) changing body and hormonal urges
- Managing menstrual hygiene
- Contraceptive medication
- Education about sex
- Discussing and redirecting inappropriate sexual behavior (touching self in public)
- Possible treatment with medication

Treatment of Seizures

- Appropriate work-up: brain imaging, electroencephalogram, possible blood tests
- Many different types of seizures
- Seizure precautions discussed
- Importance of medication compliance
- Medication treatment (depending on seizure type): Keppra, Depakote, Lamictal, Tegretol, Topamax, Zonegran, etc.

Other Medical Issues

- Choking (dysphagia)
 - Avoidance of aspiration
 - Use of a straw and modification of food consistency
 - Small and slow
- Nutrition
 - Nutritious high calorie food
 - Frequent snacks (milkshakes, ensure, muscle milk)
- Communication
 - Electronic communication devices
 - Hand gestures

Late Stage JHD

- Early discussions regarding possibilities and goals of care
- Severe stiffness in limbs leaving some children wheelchair or bed bound
- Treatment of any discomfort
- Attention to possible malnutrition, infections of the urine and lung and skin sores
- In home services and placement outside of the home
- Sensitive issues to discuss: feeding tube, goals of care, palliative care, hospice care
- Advance directive

Caregivers

- Handling the emotions of such a diagnosis
- Managing your own feelings
- Practical and emotional support
- Outlets
- Caring for the caregiver
- Support groups
- Knowing your resources
- Respite
- Create your HD family



In the moment...

- Attempt to take pause and live in the moment
- Enjoy the simple things in life
- Have the moment be NOT about JHD





Key Points

1'M A STEM CELL CHAMPION

Because:

The life of my two band for

three children depends
on it. Cure. HD

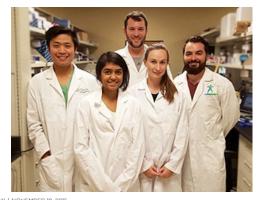
We love Dr. Nata. !

- Education
- Know where to turn for help and support
- Advocate (HD warriors)
- And maintain hope through research!



Human Mesenchymal Stem Cells Genetically Engineered to Overexpress Brain-derived Neurotrophic Factor Improve Outcomes in Huntington's Disease Mouse Models





JROLOGY TODAY | NOVEMBER 19, 2015

NEWS FROM THE SOCIETY FOR NEUROSCIENCE ANNUAL MEETING

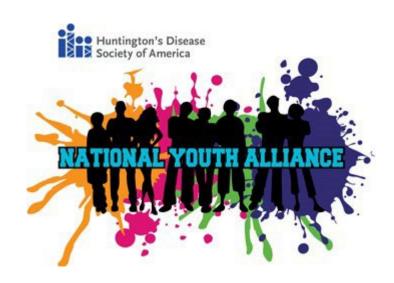
Gene Editing Techniques Show Promise in Silencing or Inhibiting the Mutant Huntington's Disease Gene





Thank you to our JHD & HD families for your strength, courage, and inspiration!







Behavior & Mood Symptoms in HD: Strategies for Patients and Families

Vicki Wheelock, MD, Lorin Scher, MD, Barbara J. Kocsis, MD, Terry Tempkin, NP, Lisa Mooney, LCSW

Psychiatric/behavioral/mood symptoms are extremely common in those with HD; in fact, most HD persons will have at least one psychiatric symptom during their lives, and some will have multiple symptoms. These symptoms in HD are a direct result of changes in the brain caused by HD. This happens because HD damages important structures and pathways in the brain—and this damage causes the problems with movement, thinking, and behavior. It is important to remember that these symptoms are caused by the illness, and not by the person suffering from HD. Understanding that behavioral issues in HD stem from a combination of brain changes and the effects of profound loss helps to guide coping strategies for patients and families.



Overview of Common Behaviors in HD

Symptom	What it looks like	Strategy to manage
Apathy	 Loss of motivation Difficulty attending to responsibilities, basic needs, and things the person used to think were important. For example: Difficulty getting out of bed or starting the day, neglecting household chores or personal hygiene Can appear similar to depression, however different than depression the person with apathy has desire to do be active, but doesn't have the motivation or drive to get it started. 	Similar strategies are helpful for managing both Apathy and decline in executive function. o medication is not very effective in treating these symptoms. Consistent routine and predictable schedule (e.g. regular meal and bedtimes, chores completed at same time each day, etc.) Cues and prompts will help with focus and completion of task. l.e. use cell phone alarms, calendars, and gentle verbal prompts Use short sentences that give 1-2 pieces of information at a time Offer choices instead of open-ended questions "Do you want oatmeal or eggs?" instead of "What do you want for breakfast?"
Declining Executive Function	 Changes present as: slower thinking, difficulty planning, challenges prioritizing, trouble organizing, less ability to concentrate, less decision-making, decreased flexibility, or decreased creativity. Example: Poor performance at work, inappropriate behavior, impulsive decision-making. 	

https://health.ucdavis.edu/huntingtons/

Symptom	What it looks like	Strategy to manage
Anxiety	 Intense feelings of inner discomfort, worry, panic, or restlessness. Example: Frequent worrying about minor or everyday things, fear of losing control or "going crazy," preoccupation with perceived judgment or scrutiny from others, obsessions/compulsions (see below). 	 Medication can be effective in helping manage Counseling or psychotherapy Maintaining a consistent and structured routine Use schedules and calendars Simplify routines Allow more time to complete daily tasks Calm environment
Depression and Suicide	 Pattern of low mood poor energy that can lead to feelings of: hopelessness and thoughts about ending life. Difficulty with concentration, tearful/crying, persistent sadness, irritability, or low energy; changes to appetite and sleep patterns; little or no interest in once pleasurable activities; preoccupation with or frequent thoughts about death or suicide. HD Persons are high risk for depression, impulsivity & suicidality. These are symptoms of HD and should be aggressively treated by medical professional. 	Be aware that suicide is common among those who suffer from HD and depression. Suicidal thoughts and statements in patients with HD should always be taken seriously and addressed immediately. Call National Suicide & Crisis Lifeline: 988 911 Or take your friend or loved oneto nearest Emergency Room for evaluation
Perseveration and Obsessive Thoughts and Compulsive Behaviors	 Fixation or being stuck on one idea or activity. (ie. ay ask same question or make the same statement over and over, fixates on specific subject, etc) Recurrent, intrusive thoughts paired with repetitive behaviors that reduce inner discomfort. Over-concern with germs/contamination, fixation on past insults/injustices	This behavior may not cause significant concern for safety or interfere with daily life or activities; however, they can be difficult for loved ones to cope with and manage. • Empathize with their feelings or actions to help them feel understood • Consistent and structured routine • Use distraction techniques • change the subject, direct attention to another task, etc • Accommodate the behavior (if safe to do so) • i.e. if wanting to always get specific food, buy the food in bulk and store out of sight, • Set appropriate limits or boundaries • Seek medical evaluation for medication

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Symptom	What it looks like	Strategy to manage
Irritability and Disproportionate Anger	 Often stems from frustration about losses (e.g. abilities, independence) combined with brain changes that decrease the ability to regulate emotions. Snappy or grouchy tone, screaming, swearing, threatening, slamming doors, hitting walls, pushing, striking or hurting others. 	 Medications are effective in helping manage Avoid direct confrontation and adopt a helpful stance when possible. Example, instead of "You can't drive because you have HD try, "I'll drive you—I was going there today anyway." This helps the person to maintain a sense of dignity and control and is less likely to trigger anger. Stop use of alcohol and substances. Though someone using these substances may feel better in the moment, substance use increases the risk of dangerous behavior and is not safe for people with HD. For sensitive issues, such as declining work performance or unsafe driving, involving outside agencies is helpful because it shifts confrontation away from family members. Soft voice, kind words, and giving space may help. If the person threatens or uses violence, it is crucial to get away and call for help (e.g. police). Do not touch or restrain an angry or aggressive person yourself. Limit stress Remove weapons from the home (guns, bullets, knives, etc) Maintain a calm, predictable environment when possible
Substance Abuse or Dependence	 Includes all alcohol, substances or drugs. cause lack of judgment, poor inhibition, impulsivity, anger outbursts, depression and other psychiatric disturbances. Abuse or dependence on substances can mask and/or intensify behavior symptoms. May be used to "self-medicate" from the symptoms of HD. Interferes and/or disrupts daily life, social relationships, work performance, etc. 	 Alcohol is a brain toxin and people with HD have less tolerance for the effects of alcohol. Marijuana and other drugs can cause and intensify hallucinations and delusions. Reduce or discontinue alcohol use (remove from home) Seek treatment as appropriate Avoid confrontations while person is under the influence

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Symptom	What it looks like	Strategy to manage
Psychosis – Delusions & Hallucinations	Delusions are false beliefs, often held with strong conviction. May be paranoid that someone or something intends to harm the individual. Hallucinations may be auditory (sounds or voices), visual (forms, animals, people) or even smells or tastes. Insight may be preserved (the person recognizes the perception is not real) or absent.	 cause may be medical (certain medications, illnesses, infections or traumas) or can be caused by recreational drugs/alcohol. Require medical evaluation Remove weapons or other means of harm from the environment Avoid use of alcohol, marijuana and other recreational drugs Involve police/911 if safety is an issue Avoid confrontation that the delusion/hallucination is untrue or unfounded Try to work around the beliefs, if safe listen distract or change subject let them express, share belief Counseling for loved ones may help identify coping strategies for the family
Unawareness	 Very common in HD Lacks insight into severity of symptoms or safety issues Failure to recognize or notice problematic behaviors or the declining ability to function. Person doesn't notice worsening performance at work, person fails to recognize they are no longer a safe driver. Unawareness and denial are often used synonymously, but they are different. Denial is psychological inability to cope with distressing circumstances, like loss of a loved one or diagnosis of a terminal disease. Often denial will decrease over time and the person will be able to process the reality. Unawareness is caused by the damage and the interruption of circuits in the brain. Denial is thought to be under the control of the individual to "protect" them from reality at that period in time, where by unawareness is not something the HD person can control as they just don't have any recognition that something is different or changed. 	 This symptom is often more problematic for the family and caregivers due to safety issues Offer incentives or rewards for cooperation i.e. offering incentives when the HD person asks others for rides to avoid driving, or staying off ladders (refraining from unsafe tasks) and willingness to allow others to assist despite they don't feel they need it Utilize creative thinking to get HD person to cooperate with a request i.e. disable the vehicle/hide keys to keep the person from driving when unsafe; hire handyman to prevent person from trying to do unsafe tasks themselves. Accept it is a symptom of HD and NOT the person being non-compliant or purposely uncooperative Try to change your response or reaction to the unawareness Use humor to cope and laugh situations off (if safe to do so)



It may not always be clear why a person is behaving a certain way. It is important to be aware of any changes that you or your loved one may be experiencing. Some changes indicate that immediate help or intervention

may be required. Seek immediate help for the following:



Alcohol or recreational drug dependence or abuse



Anger and aggressive behavior



Depression with thoughts of suicide, self-harm or injury



Paranoid thoughts



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Command hallucinations (voices) directing the person to harm themselves or others

Crisis Interventions

When you or your loved one is experiencing a behavioral crisis there are some interventions that may be available to evaluate and address the concern safely.

911 or Police Involvement

911 and/or police should be called when the safety of any person is in jeopardy

Can help de-escalate situations and determine next step to resolve issue

Emergency Room Visits

Rapid medical and psychiatric evaluation

Come prepared with information about symptoms, behavior issues and length of

Bring list of all medications, include any known alcohol or substance use

Medical Hospitalization

Admission into hospital for medical issue needing immediate intervention: medication and/or observation to stabilize or prevent worsening of symptoms.

Psychiatric Hospitalization

Admission directly (voluntary or involuntary) to a facility specializing in mental illness to start/adjust medications and/or observation to stabilize.



Additional Resources



HD Medical Team or HD Social Worker Lisa Mooney Ikjer@hdsa.org 916.734.6277



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



Help4HD

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



Suicide Prevention Lifeline

988; http://suicideprev entionlifeline.org/

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



Tel: 916-938-3576

Counseling

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

What are the treatments for depression?

There are many strategies for treating depression and healthcare professionals may suggest one or more types of treatment to target a particular individual's depression symptoms.

Therapy

Talking with a therapist or counselor can help people with depression. There are two main types of psychotherapy, or "talk therapy", commonly used to treat depression.

Cognitive behavioral therapy (CBT) and interpersonal therapy (IPT). CBT teaches people to change negative ways of thinking and behaving that may contribute to their depression. IPT helps people understand and work through troubled personal relationships that may cause their depression or make it worse.

For mild to moderate depression, psychotherapy alone can be as effective as medications. However, for more severe depression, psychotherapy and medications are recommended.

Medications

Medications help balance chemicals in the brain called neurotransmitters. Different types of medications affect different chemicals in the brain.

Medications affect everyone differently. Sometimes several different types have to be tried before finding the one that works. If you start taking medication, track any side effects, and tell your doctor about them right away.

Lifestyle changes

Lifestyle changes, including improving sleep, nutrition, physical activity and exercise, and stress management can also be very powerful in helping to reduce or manage symptoms.

How can I help myself if I am depressed?

You may feel exhausted, helpless and hopeless. These feelings are the part of the depression and do not accurately reflect actual circumstances. As you begin to recognize your depression and begin treatment, negative thinking will fade.

Set realistic goals for yourself and break up large tasks into smaller ones. Set priorities and do what you are able as you are able.

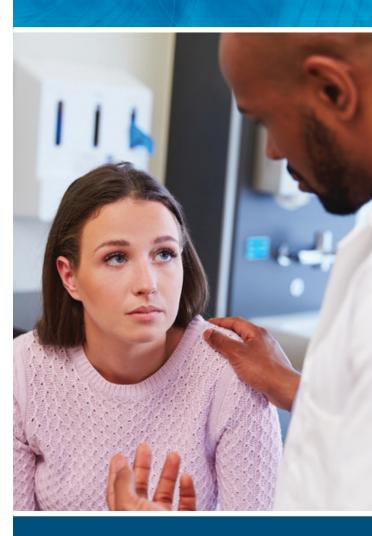
Try to spend time with other people and confide in a trusted friend or relative. Try not to isolate yourself, and allow others to help you.

Expect your mood to improve gradually, not immediately. Often during treatment for depression, sleep and appetite will begin to improve before your depression lifts.

Postpone important decisions, such as getting married or divorced, or changing jobs, until you feel better. Discuss decisions with others who know you well first.

Learning about depression

Depression is a real illness



What is depression?

Depression is an illness that impacts the brain. Everyone occasionally feels sad or down, but the feelings are usually fleeting and pass within a couple of days. When a person has a depressive disorder, it interferes with daily life, normal functioning, and causes pain for both the person with the disorder and those who care about him or her. According to the World Health Organization, an estimated 21% of women and 12% of men in the U.S. will experience depression in their lifetime. Depression is a common and serious medical condition, and most who experience it need treatment to get better.

Forms of depression

There are several forms of depressive disorders. The most common are major depressive disorder and dysthymic disorder.

Major depressive disorder, also called major depression, is characterized by a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy once-pleasurable activities. Major depression is disabling and prevents a person from functioning normally or feeling well.

Dysthymic disorder, also called dysthymia, is characterized by long-term (two years or longer) but less severe symptoms that may not disable a person but can prevent one from functioning normally or feeling well. People with dysthymia may also experience one or more episodes of major depression during their lifetimes.

Signs and symptoms of depression

Not everyone with depression will have all of these symptoms. The signs and symptoms of depression are often different in men and women, children and adults.

Feelings

- Ongoing sad, anxious or empty feelings
- Feelings of hopelessness
- Feelings of guilt, worthlessness, or helplessness
- Feeling irritable or restless

Thoughts

- Difficulty concentrating, remembering details
- Difficulty making decisions
- Thoughts of suicide or attempting suicide

Behaviors

- Loss of interest in activities or hobbies that were once enjoyable, including sex
- Withdrawing from people
- Substance abuse
- Missing work, school or other commitments

Physical problems

- Feeling tired often or all the time
- Changes in sleep patterns
- Overeating or loss of appetite
- Ongoing aches and pains, headaches, cramps or digestive problems that do not go away

Why do people get depressed?

Depression occurs when there are changes in a person's brain chemistry. Additional factors, such as changes in hormone levels, medical illness, stress, trauma, loss or grief, or challenging circumstances and lifestyle choices.

Depression can be different for men and women and at different points during a person's lifetime. Women are twice as likely to experience depression than men, and the peak onset of symptoms is between ages 15-24.

Depression can occur from a variety and combination of factors:

Genes

Some types of depression are passed on genetically and run in families. Genes are the "blueprints" for who we are, and we inherit them from our parents.

Brain chemistry and structure

When chemicals in the brain are not at the right levels, depression can occur. These chemicals, called neurotransmitters, help cells in the brain communicate with each other. By looking at pictures of the brain, scientists can also see that the structure of the brain in people who have depression looks different than in people who do not have depression

Environmental and psychological factors

Trauma, loss of a loved one, a difficult relationship, and other stressors can trigger depression. Scientists are working to figure out why depression occurs in some people but not in others with the same or similar experiences. They are also studying why some people recover quickly from depression while others do not.

Light

Natural light can help lift your mood. Being outside or near a window for even a few minutes a day, is beneficial.

Sleep

Sleep is a problem for many with depression, either sleeping too much or too little. Some tips for better sleep are:

- Go to bed and get up at the same time.
- Limit or eliminate daytime naps.
- Have a nighttime routine.
- Limit the amount of time you lay awake in bed. If you haven't fallen asleep within 30 minutes, get out of bed for a short while and try again later.
- Be aware of your caffeine and alcohol intake which can worsen sleep problems.

Education

Learning about depression and your particular symptoms is a very useful tool. Understanding your medical condition better can help you make changes, track your progress and alert you to any change in symptoms later on. Your depression care manager or physician can suggest some good books and websites.

Movement

Most people who struggle with depression have low energy. Taking a short walk, even beginning with 5 minutes a day, can make a difference.

Social

Even though you may not feel like being around others, socializing is an excellent self-management tool. Consider doing something you used to enjoy. To prevent being overwhelmed, keep the activity simple and time-limited

Nutrition

Making simple changes to your eating habits can make a big difference over time. One example of a simple change is to add a vegetable or fruit to your daily intake.

Support

Talking with those who understand depression is also beneficial. If you don't have support people in your life, consider joining a support group in your area or online. Your depression care manager may be able to help you find one.

Mindfulness and stress management

Exploring different approaches to managing stress can be a valuable tool to those who are being affected by the stress in their lives. You can learn mind-quieting meditation techniques, calm breathing exercises, and discover gentle body movements and stretches that help reduce stress. Classes are available at UC Davis Medical Center.

Visit **livinghealthy.ucdavis.edu** for additional information, upcoming classes, tools and resources.

Taking care of yourself

Managing your depression



Avoiding depression can be thought of as fighting off a cold. If you take care of yourself at the first signs of a cold, you may be able to prevent it from getting worse. But if you ignore the body's warning signs, the cold may become more serious. The same principle is true for depression. Listed below are three common phases of depression:

Green light phase

This is the phase when your symptoms are mostly gone and you feel good most of the time.

Things to do during the green light phase:

- ☐ Stay on your medication and keep all follow-up appointments with your doctor. Although it may be tempting to stop your anti-depressant medication when you feel better, but it could lead to a return of depression. Talk to your doctor before changing or stopping medication.
- ☐ Identify your symptoms. It's important to know your own symptoms so you recognize them quickly if they return. Take a few minutes and list the main symptoms you struggled with before you improved.
- Continue good self-care skills.
- Identify and engage a support person to help you recognize depression symptoms if they return.

Yellow light phase

This is the phase when you may begin to notice depression symptoms. Changes in sleep patterns and appetite are common. You may have less energy or be more irritable. This is the time to act, before symptoms get worse.

Things to do during the yellow light phase:

Contact your support person to let them know your depression symptoms may be back. Ask if they have noticed any changes in your behavior or mood. Ask for their support.

- ☐ Call your physician for an appointment.
- Call your therapist for an appointment. If you do not have a therapist, consider finding one.
- ☐ Take a day off from responsibilities to relax and evaluate. Consider the following:
- What can I do to immediately relieve some stress? (i.e. postpone major decisions, life changes ask for help with responsibilities)
- Am I taking care of myself all the ways that I can?

Red light phase

This is the phase when you may be experiencing another depressive episode. You notice many of your symptoms have returned. Again, the sooner you get help, the sooner you can get better.

An immediate plan of action is:

- Do not wait any longer to seek help.
- Return to the things that have helped you get better in the past, if applicable.
- □ Call your doctor's office for an urgent appointment. Be honest about the severity of your symptoms.
- If you feel like hurting yourself or others, tell someone right away.
- ☐ Take at least three days off from all responsibilities, if possible, and use this time to increase self-care and seek support.

Numbers to call are:

- 911
- Suicide Prevention Lifeline: 1-800-273-8255
- Doctor's office:
- Support person:

Tools for your tool-kit

Think of these tools as part of a depression "tool-kit". Just as you would need several tools to work on a project at home, you also need multiple "tools" to manage depression. Using these tools can set the wheels in motion toward getting and feeling better.

Start with just one tool and consider adding another as the first becomes easier. The order you choose is up to you.

Start — don't wait until you "feel" like doing it — take action and the feelings will follow.

Know your limits. There is a delicate balance between striving towards health and pushing yourself too much. Only you know how much you can realistically do.

Medications

Taking your medications as prescribed is very important for managing depression. Using a pill box is one way to remember your daily medication. Consider keeping a log of any side effects or changes to bring to your appointments. This helps your doctor help you.

Relaxation

You may not believe you "deserve" to relax because of low energy and/or negative thinking, but this is the best time to take care of yourself, just as you would if recovering from a physical injury or illness. You may find little things relaxing, such as taking a bath, lighting a candle, smelling a favorite scent, interacting with a pet, or listening to soothing music. Try engaging in an enjoyable activity or exercise.

Water

Drinking enough water helps your body and brain function properly. Try adding just one extra glass of water to your daily routine.



Cognitive Changes in HD

Vicki Wheelock, MD

Cognitive changes are among the most debilitating aspects of HD. Subtle changes start early in HD, even prior to diagnosis and eventually leads to reduced job performance and contribute to loss of functional abilities. These changes in functional abilities can also create stress for the entire family. <a href="Month Report Subtle Property of Subtle Prop



Definitions of Cognitive States

Normal

• No Symptoms, normal test performance

Mild Cognitive Impairment

 Impairment in at least ONE cognitive domain without a loss of functional independence

Dementia

• Impairment in at least TWO domains of cognition with functional impairment.



Testing Cognitive Function & Medical Management

- •Mini Mental Status Exam (MMSE)
- •Montreal Cognitive Assessment (MOCA)
- •These used to monitor changes to the brain/cognition.
- Often done annually

In clinic testing



- NeuroPsychological Exam
- •can take 4-6 hours to complete full assessent.
- Often ordered IF person is still working to establish baseline.
- Then can be redone IF work challenges/difficulties are happending to support DISABILITY claim.
- Helps with understanding the persons cognitive abilities -- often can help familly set realistic expectations

FORMAL Assessment



 Help patient, providers and families identify areas of difficulty and establish accomodations to assist.

BENEFITS







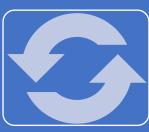
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Impacts of Cognitive Changes — changes in thinking abilities can interfere with many aspects of life such as work performance, ability to safely live or be independent, ability to manage one's responsibilities and even impact one's ability to care for their personal needs.



Disorganization Difficulty

- •keeping up with finances or paperwork
- •Lose important papers without a 'system' to keep organized.
- •keeping track of appointments or schedules
- prioritizing or sequencing tasks (i.e. follow recipe, develop meeting agenda, fill out detailed forms, etc.)



Apathy

- Difficulty getting started on tasks
- Difficulty with completing or following through on tasks
- •Often content with watching t.v. (same show sometimes) for long periods of time.
- May not keep up with hygiene
- Apathy is NOT laziness and can often appear to be depression but they are different.



Problems with 'mental flexibility'

- •only seeking something ONE way.
- •getting stuck/fixated on topics.
- •difficulty letting go or moving from thought or idea.
- •Unable to do focus or do more than one thing at a time (i.e. watch tv & listen, drive & have conversation, etc)
- Easily distracted by other things in the enviornment
- Feeling of overwhelm or tiredness in new, large or chaotic (ie. lots of noise or stimuli) environments.



Processing Speed reductions

- Needs more time to complete tasks.
- Needs reminders of the steps in complex tasks
- Daily tasks/acitivies are more draining or stressful than they used to be.

Impacts of Cognitive Changes (continued)

Poor Judgement

- Not able to weigh or foresee consequences of decisions
- may make bad decisions at work, or with money that doesn't seem logical or reasonable
- can impact able to maintain or recognize unsafe situations



Problems tracking time

- trouble estimating how long a task will take.
- difficulty judging how much time has elapsed.



Reduced Impulse Contral

- may say things without thinking it through first
- difficulty regulating eating, smoking, sexual behavior
- often will get a thought in head and will act before recognizing whether its a good idea or not (i.e. shoplifting, internet shopping, etc.)



Memory

- will have trouble with short term memory and recalling conversations, remembering events (birthdays, anniversaries, etc).
- may need reminders (verbal or calendar) to complete tasks (bathing, changing clothes, etc)



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→ Strategies for Managing Cognitive Changes

Communication

- Give time to respond -- slower process can cause delay in response time.
- give time or help (if wanted) to find the "right words" as the HD person may struggle to find the word they want to use.
- One conversation at a time -- may have difficulty tracking a complex or multiple conversations.
- Forgive and redirect if they go off topic.
- make sure to have eye contact and be facing the person when talking for better engagement.
- Multiple choice questions, yes/no can assist when communicating needs/desires.

Limit Distractions

- Focus on one task at a time (i.e. turn off radio or limit talking when driving or eating, etc)
- Have quiet, comfortable location to work/complete tasks
- One question at a time (minimize stimulus overload).



Use HUMOR

Always remember to laugh when possible. Mistakes and plans/routines will NOT always go as planned so laugh, learn and try again tomorrow!

Memory

- Provide hints/reminders to assist with recall.
 may experience some difficulty with short term memory or learning new information
- If learning something new, teach in small increments
- Use notebooks, lists for remembering
- calendar of events, birthdays, etc.

<u>Simplify</u>

- Break large tasks into smaller easier to manage steps
- Keep consistent and routine schedule as much as possible.
- Allow extra time
- Keep trips short and go to familiar locations



Plan for Changes

- have a plan on how to address changes in routine.
- When anxiety or repetitive thoughts arise, use distraction, change environment, get out of the house, change of scenery.

External Aids

- Daily "to-do" lists -- plans out the day without having to think about what's next.
- Use calendar for visual cues of what's happening next.
- Use alarms or reminders on smart phones or smart home devices (Alexa, google home, etc)



DAILY Schedule Recommendations



- LIMIT Activities to 3-5ish per day. Goal is to BE SUCESSFUL
- Sample activites/tasks to include in routine: walk dog, exercise, make bed, shower, household chores, daily/standing appointments, watching favorite t.v./movie, etc.
- May be more successful IF you create a FAMILY schedule and/or schedule for EACH person in household in effort to NOT single out anybody.



WEEKLY/MONTHLY Schedule Recommendations

Water Plants
Change Bed F Grocery Shopping Physical NEDNES Pay Bills Shower Wedical Appointment Volunteer Shopping Activities **Appointment** Laundry Lunch with sheets Therapy Friend Activities/Tasks to include in routine: walk dog, exercise, make bed, shower, Church Grocery household chores, Shopping appointments, watching Shower favorite t.v./movie, social events/plans, etc Outing with Family



Suicide Prevention Emergency Contacts

9-1-1 should be contacted if you or your loved one is in immediate danger and needs urgent medical attention. Please remember that there is someone who cares and is willing to listen and speak with you when you are feeling depressed and/or suicidal. People do care about your safety and well being.

County/City	Populations Served	Name	Contact Information	Description of Services
Statewide	All	Emergency Medical Response	9-1-1	Emergency Medical services will be dispatched to your given location within minutes of calling.
Nationwide	All	National Suicide Prevention Lifeline	988 (telephone or text)	24 hour hotline with trained counselors available to listen and talk with you.
Nationwide	All	Disaster Distress Helpline	1-800-985-5990 Text: "TalkWithUs" to 66746 https://www.samhsa.gov/find- help/disaster-distress-helpline	24/7, 365-day-a-year, national hotline dedicated to providing immediate crisis counseling for people who are experiencing emotional distress related to any natural or human-caused disaster. This toll-free, multilingual, and confidential crisis support service is available to all residents in the United States and its territories. Stress, anxiety, and other depression-like symptoms are common reactions after a disaster.
Nationwide	Seniors	Institute on Aging	1-800-971-0016	24 hour suicide and grief friendship line for the elderly offering telephone support to depressed, isolated, abused and/or suicidal older adults
Nationwide	All	National Alliance for Mental Illness	1-800-950-NAMI Text: "NAMI" to 741741 https://www.nami.org/Home	24/7, confidential and FREE crisis counseling line for people. NAMI can help link you with local or virtual services as needed.
Nationwide	Spanish Speaking	Suicide Hotline in Spanish	1-888-628-9454	24 hour crisis hotline
Nationwide	LGBTQ	The Trevor Project	1-866-488-7386 https://www.thetrevorproject.org/	Crisis intervention and suicide prevention for lesbian, gay, bisexual, transgender and questioning youth.
Nationwide	Veterans	Veterans Crisis Line	1-800-273-8255, press 1 Text: 838255	24 hour Confidential live veterans chat
Nationwide	Youth	YouthLine	1-877-968-8491 Text: "teen2teen" to 839863 https://oregonyouthline.org/	Youth America Hotline, counseling for teens by teens. Online chat available too!
On-line	All	Crisis Chat	www.crisischat.org	Online emotional support. Hours vary 12 hrs day/7 days week
On-line	All	I'm Alive	www.imalive.org	Online crisis network suicide and crisis chat. Available 24 hours day.



Exercise Therapy for Huntington's Disease

Michael Sterken, PT, DPT, NCS

ALL STAGES

- Consult with a physical therapist who is familiar with HD to assist with designing, implementing, progressing, and adapting activity programs to optimize health, function, and safety.
- Consider meeting with a certified personal trainer to ensure exercises and activities are performed correctly.
- Stop activity and consult with a physical therapist or your physician if any activity or exercise you do results in pain or injury.
- Remember that physical therapists also teach caregivers how to safely engage in patient handling, recommend
 environmental modifications to improve functional mobility/safety, and suggest adaptive equipment to help you
 and your loved ones to maintain safety and mobility.

EARLY STAGE (PRE-MANIFEST/STAGE 1)—PREVENTATIVE ACTIVITY

Cardio!!! (Power walking, jogging, cycling, rowing, stairs, elliptical, yard work, etc.)

- Find something you enjoy and recruit other people to do it with you to increase your compliance.
- How often: 3-5X/week
- How long: 30-60 minutes per session
- How intense: 60-80% of heart rate max; should have to take a breath if trying to speak a sentence
 - \circ 220 your age = your heart rate max. (HR max X 0.6 = 60% of your HR max)
- Why: Intensity & duration of cardio correlates with increased levels of <u>Brain-Derived Neurotrophic Factor</u> (BDNF).
 - BDNF is a protein that supports differentiation, maturation, and survival of neurons in the nervous system and <u>stimulates and controls growth of new neurons</u> from neural stem cells (neurogenesis). BDNF may provide <u>neuroprotective effect</u> against the neurodegenerative effects of Huntington's Disease.
- What? Cardio may slow progression of the disease and preserve functional independence longer.

EARLY-MIDDLE (STAGE 2)—RESTORATIVE ACTIVITY

Continue Cardio!!

See information for Stage 1 above for examples of cardio activities/exercises, frequency and intensity.

Strength Training (Pushing, Pulling, Rising/Lowering, and Abdominals)

- How often: 2-3X/week
- How long: approximately 20-30 minutes



https://health.ucdavis.edu/huntingtons/

- How much: 2-3 sets of 8-12 repetitions of at least 4 exercises with approximately 1-minute rest between sets
- How intense: Muscle should fatigue by the end of 8-12 reps without loss of proper form/posture
- Why? Muscle weakness is common in later stages of HD and may contribute to loss of function

Balance Training (Tai Chi, Yoga, Pilates, Single leg standing, slow marching, tandem walking, etc.)

- How often: 2-3X/week
- How long: 10-30 minutes
- How intense: Exercises that challenge your stability, requiring concentration, but not so hard you fall
- Why: Balance worsens over time without practice = Falls = Injury = Loss of independence

MIDDLE-LATE (STAGES 3-4)—RESTORATIVE/COMPENSATORY ACTIVITY

Continue Cardio by modifying what you do in order to stay safe while being active.

- Engage in a walking program using an assistive device (a 4-wheel walker or platform U-step walker)
- If you can't walk safely consider propelling a wheelchair or riding a recumbent bike with safety straps

Continue Strength training by modifying exercises to accommodate motor symptoms.

- Machines and body weight exercises tend to be more accommodating than free weights.
- Seated or in-bed exercises tend to be more accommodating than standing exercises.

Continue Balance training by modifying exercises to minimize the risk of falling.

Focus on static/stationary balance over dynamic/moving balance & avoid multi-tasking.

Flexibility training (stretching only tight muscles)

- How often: 2-7 days/week
- How long: 30-60 seconds per muscle group
- How intense: Holding end-range should be mildly uncomfortable, but NOT painful
- Why: As HD progresses people tend to get less active, more muscle tightness, and reduced joint motion

LATE (STAGE 5)—COMPENSATORY/PALLIATIVE ACTIVITY

This stage is when care providers are responsible for assisting the HD person in effort to maintain active movement.

Continue assisting with Flexibility training (See Middle-Late stage above)

- Focus on positioning the person with HD to minimize pressure and friction over bony prominences
- Use support pads/straps to help the person with HD be comfortable and move, if able



PHYSICAL ACTIVITY AND HUNTINGTON'S DISEASE

PHYSICAL ACTIVITY BENEFITS:

- General health benefits
- Improved sleep
- Managing anxiety and depression
- Improved quality of life

SPECIFIC BENEFITS FOR HD:

- Improved balance confidence
- Improved mobility
- Improved independence
- Improved posture and breathing

EXAMPLES OF PHYSICAL ACTIVITY AND EXERCISE











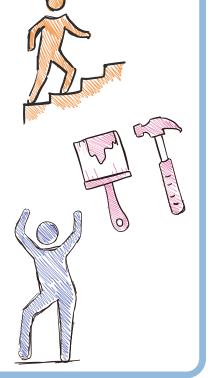




MOVING MORE AT HOME









MY PHYSICAL ACTIVITY PLAN

Name: Date: WHAT'S IMPORTANT TO ME ...AND I LIKE DOING?

WHICH PHYSICAL ACTIVITY/ EXERCISE DO I DO NOW? WHAT WOULD I LIKE TO BE ABLE TO DO?

WRITE YOUR THOUGHTS AND IDEAS HERE...

What will I do?

How often will I do it and where?

How will I track my progress?



Who can I ask for advice?

e.g. HD advisor, HD clinic, local leisure centre



What support do I need?

e.g. family, friends, carer



What is stopping me doing activity?

e.g. planning, movement problems



This exercise programme has been developed by physiotherapists specifically for people with movement disorders. Exercise is not without its risks and this or any other exercise programme has potential to cause injury. To reduce the risk of injury, consult your doctor or physiotherapist before beginning this exercise programme. Your physiotherapist should be able to help you identify which exercises will be most beneficial for you or if you should modify or omit any of the exercises in the DVD. The exercises presented here are in no way intended as a substitute for medical consultation; the authors and producers disclaim any liability from and in connection with this program. As with any exercise programme, if at any point during your work out you begin to feel faint, dizzy or have physical discomfort, you should stop immediately and seek medical advice.

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Acknowledgements:

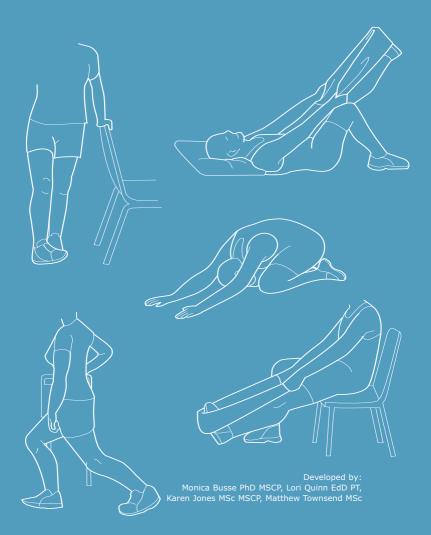
The contributions of the specialist physiotherapists and occupational therapists to the development of this DVD is gratefully acknowledged. This work was funded by a grant from the Chief Medical Officer for Wales Research Budget, Welsh Assembly Government

Video production, graphic design and illustrations by Media Resources Centre University Hospital of Wales.



MOVE TO EXERCISE

An exercise programme for people with movement disorders



About these illustrations

This booklet is intended as a supplement to the DVD - you will need to use the DVD to hear detailed instructions. The diagrams shown illustrate the different exercises that are demonstrated in the DVD; you should use these diagrams to remind you of the correct activities when you work through the exercise programme. The purpose and a few important points relevant to each exercise are shown. Specific instructions relating to the number of repetitions recommended or the length to hold a particular stretch are provided on the DVD.

You will see that the exercises can be performed in standing or in sitting; you should choose the option where you feel most safe. If you are doing the exercises in standing, you should have a sturdy chair close by for balance and support if needed.

Correct Posture

Purpose: In order to get the most from the exercises in this programme, it is important to maintain a good

posture whilst you are doing them.

Key points: Try to achieve a comfortable, upright position. Your back should not be overarched or slouched.



Routine to practice getting up and down from the floor using a chair

Purpose: It is important that you can get down and back up from the floor safely.

Key points: You should only start the mat-based exercises when you feel safe and confident with getting down and back up from the floor; this may take a few sessions of chair to floor to chair practice.



1.0 FLEXIBILITY AND WARM UP

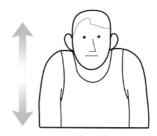
1.1 Neck Stretches

Purpose: These exercises stretch the muscles on the front, back and side of your neck; you should start gently. These stretches are important for maintaining good posture, and mobility in your neck and shoulders.

Key points: Try not to let your shoulders lift during these movements.

1.2 Shoulder Rolls

Purpose: This exercise helps to achieve a good posture, and maintains mobility in your shoulders and upper back. Key points: Shrug your shoulders up towards your ears. Now slowly roll them backwards and downwards whilst trying to squeeze your shoulder blades together.



1.3 Horizontal Shoulder Flexion

Purpose: This exercise stretches the muscles in your upper arm, upper back and shoulder.

Key points: Take your right arm and gently bring it across your chest at the height of your shoulder. With your other

hand, gently hold your right elbow and pull your arm further across. You should feel the stretch across the back of your arm, and your shoulder. Repeat this with your left arm.



1.4 Arm Circles

Purpose: This exercise helps with flexibility and mobility of the entire shoulder joint, and also helps with your posture.

Key points: Keeping your elbow straight, move your right arm in a big circle in a forward direction. Repeat in a backward direction. Now repeat with your left arm in both directions.



1.5 Hand Stretches

Purpose: This exercise helps with mobility of your hands and wrists.

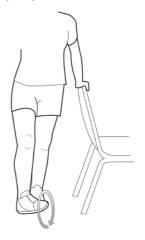
Key points: With your elbows bent, rotate both your hands around in a circle, and repeat in the other

direction.

1.6 Ankle Circles

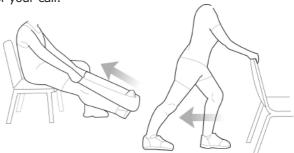
Purpose: This exercise helps with the flexibility of your ankles.

Key points: Standing with a chair nearby for support, make circles with one foot, first in one direction and then the other direction. Repeat with the other foot. If you feel as if you will lose your balance, put your foot down. Once you have regained your balance, try again.



1.7 Calf Muscle Stretches

Purpose: This exercise stretches your calf muscle. It is an important muscle for walking and balance. Key points: In standing, step back with one leg, bend your front knee and lean forward. Keep your back knee straight, and you should feel a stretch in the back of your calf. Taking a wider stance will make this stretch more intense. If you do this in sitting, wrap a towel around the ball of your foot, pulling your upper foot towards your body. Feel the stretch in the back of your calf.



1.8 Hamstring Stretch

Purpose: This exercise stretches the hamstring muscles, at the back of your thigh.

Key points: Lying on the floor, wrap a towel around your foot and pull your leg up towards your body, keeping your knee straight and your foot bent. You should feel the stretch in the back of your leg.

1.9 Lying Supine Twist

Purpose: This exercise helps with mobility of your trunk and your hips.

Key points: Bend both of your knees, keeping your feet flat on the floor. Spread your arms out to the side. Drop your knees over to one side, and turn your head in the opposite direction. Now drop your knees to the other side, and turn your

head in the opposite direction.

1.10 Thigh stretch

Purpose: This stretches the quadriceps muscle in the front of the thigh. It is an important muscle for such activities as rising from a chair, and climbing stairs.

Key points: Whilst lying on your stomach, place one hand at the ankle and bend that knee so that your heel comes towards your bottom. Gently pull that leg until the front of thigh stretches. If you can't reach your ankle, use your other leg to help move your heel toward your bottom. Feel the stretch in the front

of your thigh.

1.11 Prone Press Ups

Purpose: This exercise promotes mobility of your low back, and counter-balances the effects of sitting and being in a forward flexed position for long periods of time. Key points: Start lying on your stomach. Place your hands at your sides near your shoulders, and press up by straightening your arms. When doing this exercise; be careful not to lift your hips or legs up off the floor. Do not do this exercise if it hurts your back, or if you feel any pain going into your buttocks or your legs.

1.12 Kneeling Child's Pose

Purpose: This exercise stretches out your spine and improves the flexibility of your hips and knees.

Key points: Start by lying on your stomach, move onto all fours, then gently sit back on your heels. Keep your arms stretched out in front of you. Try to sit all the way back on your heels.

2.0 BALANCE AND CO-ORDINATION

2.1 Standing with feet together, eyes open and then closed

Purpose: This exercise aims to improve your standing balance and your balance during walking.

Key points: In standing, try to maintain your balance. If you feel comfortable in this position, close your eyes for up to 10 seconds, but be sure your hands are near to the chair

for support if you need it.

2.2 Standing on one leg

Purpose: This exercise aims to improve your standing

balance and your balance during walking.

Key points: In standing with support, bend one knee so you are standing on one leg.

If you lose your balance, put your foot down, regain your balance and try again.

If you feel comfortable in this position, let go of the support

while keeping your hand nearby.

2.3 Tandem Standing

Purpose: This exercise will improve your standing balance and your balance during walking.

Key points: Place one foot in front of the other. If you can, put the heel of your front foot against the toe of your other foot. If you are unable to keep your balance in this position, put your front foot to the side but as close to the other foot as is comfortable. If you feel comfortable in this position, let go of the support while keeping your hand nearby.



2.4 Forward Lunges

Purpose: This exercise works to strengthen the

quadriceps muscle that is important for walking.

Key points: Standing with a chair near to your side, take a step forward with your right leg, hold for a second, and then return to the starting position. Use the chair

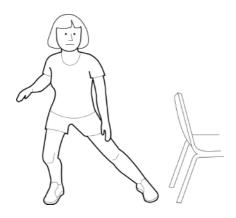
to help you keep your balance if you

need support.

2.5 **Side Lunges**

Purpose: This exercise works to strengthen the hip as well as the quadriceps muscles of the leg that are important for walking.

Key points: Standing with the chair at your side, take a comfortable step out to the side, bending your knee over your ankle. Use the chair for balance if needed.



3.0 CIRCUIT RESISTANCE TRAINING

3.1 Sit to stand repetitions

Purpose: This is an important exercise to help improve your ability to get in and out of chairs easily, as well as

strengthen your quadriceps muscles, which are important for stair climbing and walking. Key points: From a sitting position, lean forward over your thighs and come to a standing position. Once you have your balance, carefully lower yourself back into the chair.



3.2 Shoulder press with weights

Purpose: This exercise strengthens the shoulder

and back muscles, which are important for all daily activities. Remember to stand with a good relaxed and upright posture.

Key points: Hold one weight firmly in each hand. Bend your elbows so that your hands are near your shoulders. Slowly push your arms straight up into the air. Be careful not to arch your back. Slowly return the weights to shoulder height.



3.3 Squatting

Purpose: This exercise helps to strengthen the quadriceps and gluteal muscles which are very important for many daily activities such as sitting down and standing up from a chair, walking and climbing stairs. Key points: Start by standing near a sturdy chair, facing away from it as if you were going to sit down in the

chair. Gently bend your knees and squat down, as if you were going to sit on the chair. Come as close as you can to the chair without actually sitting on it. Now stand up while squeezing your buttocks.

3.4 Shoulder abduction with weights

Purpose: This exercise strengthens the shoulder muscles and back muscles, which are important for all daily activities. Remember to stand with a relaxed and upright posture, with your knees slightly bent.

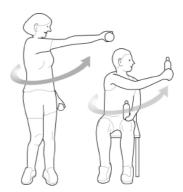
Key points: Holding a weight in each hand, keeping shoulders relaxed and elbows straight, move your arms out to the side until shoulder level then return back to the starting position.

3.5 Trunk rotations & reaching with weights

Purpose: This is an important exercise for strength of the trunk and to help with balance.

Key points: Holding a weight in each hand, reach with

your right hand across your chest to the left side. Turn your body as far as you can comfortably move. Return back to centre, and then repeat to the other side. You can also do this exercise in sitting.



3.6 Step Ups

Purpose: This is an important exercise to strengthen the muscles of the hip and thigh.

Key points: Standing facing a stair, bring your right foot up and step up onto the stair. Follow with your left foot. Now step back down onto the floor, leading also with your

right foot. Now repeat, leading with the left foot. Make sure there is a railing for support if needed. If you don't have stairs at home, you can march on the spot bringing your knees upwards towards your chin. Make sure there is a chair nearby for support.



4.0 STRENGTHENING

4.1 Bridging

Purpose: This exercise strengthens your buttocks and your leg muscles. This is particularly important for

balance and walking.

Key points: Bend both of your knees so that your feet are flat on the floor. Gently tilt your pelvis, as if you are imprinting your back into the floor.

Now, lift your hips up into the air, while still holding your pelvis level.

4.2 Alternate Arm and Leg Raises

Purpose: This exercise strengthens your back muscles and helps with your posture

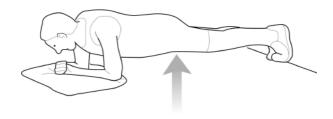
Key points: Lying on your stomach, turn your head to one side so that you are comfortable. Slowly lift your right leg into the air. You should be able to raise your foot a few inches from the floor and hold for a short while. Repeat with the other leg. Progress by lifting the left arm with the right leg;



4.3 Plank

Purpose: This exercise strengthens your back and stomach muscles.

Key points: Lying on your stomach, prop yourself up onto your elbows. Now, curl your toes under and lift yourself up onto your feet, while staying supported on your elbows. Try not to lift your hips up too high in the air. Hold this position for as long as you can (up to 10 sec). Rest as needed and then try again.



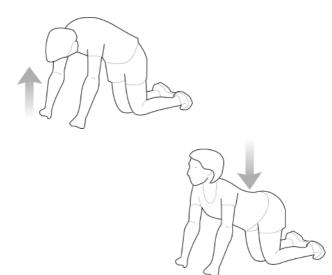
5.0 COOL DOWN AND RELAXATION

5.1 Cat/Camel stretch

Purpose: This exercise helps to stretch your spine and helps with improving the mobility of your trunk.

Key points: Start on your hands and knees, with your knees directly underneath your hips, your hands underneath your shoulders and back flat. Lay your hands out flat. Now as you take a deep breath in, arch your back, pulling your belly button away from the floor and bending your head so that you look at your stomach. Now exhale and move your spine in the opposite direction, pushing your belly button towards

the floor and lifting your head up to look towards the ceiling.



5.2 Trunk Rotations

Purpose: This exercise helps with mobility of your trunk and your hips.

Key points: Bend both of your knees, keeping your feet flat on the floor. Spread your arms out to the side. Drop your knees over to one side, and turn your head in the opposite direction. Now drop your knees to the other side, and turn your

head in the opposite

direction.

5.3 Breathing exercises

Purpose: Breathing exercises help with relaxation after exercise.

Key points: Lying on your back, with your knees bent, place your hands on the lower part of your stomach, and inhale deeply through your nose, then exhale though your mouth,

and relax.

Notes

https://health.ucdavis.edu/huntingtons/



Know Your Therapist—A Who's Who Guide

Michael Sterken, PT, DPT, NCS

TYPES OF MEDICAL THERAPISTS

Physical Therapist (PT)—A State-licensed clinician who specializes in human movement. A PT has extensive training in analyzing movement to diagnose and treat impairments that may result in pain, dysfunction, and/or disability. Physical therapists help people to set goals and implement interventions to optimize their performance, maximize their functional mobility, and promote their independence. You do NOT require a physician referral to be evaluated and treated by a PT, but most insurance companies do require physician authorization for reimbursement. Most PTs are general practitioners but there also many PTs who have a board certification or sub-specialty one or more of the following areas: Orthopedics, Geriatrics, Neurology (NCS), Sports, Pediatrics, Women's Health, Cardiovascular & Pulmonary, Clinical Electrophysiology, Oncology, Wound Care, & Vestibular rehab. Typical entry-level training for a PT is to obtain a bachelor's degree and then complete two and a half years of graduate-level academics and nine months of clinical internships to obtain a Doctorate.

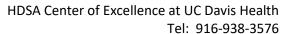
Physical Therapist Assistant (PTA)—A State-licensed clinician who works under the supervision of a PT to implement the physical therapist's plan of care. PTAs are experienced in teaching, observing, and progressing the plan of care developed by the PT. Typical entry-level training for a PTA is two and a half years of academics and three months of clinical internships to obtain an associate degree.

Occupational Therapist (OT)—A State-licensed clinician who specializes in optimizing a person's ability to successfully and independently perform activities of daily living (ADLs) such as dressing, bathing, grooming, toileting, hygiene, and eating. OTs also help train people to perform more advanced activities such as completing chores, meal preparation, organizational skills, and school/work task completion. Most OTs are general practitioners, but there are also many OTs who have subspecialties in Gerontology, Pediatrics, School individual education planning, Mental Health, Assistive technologies, Driving/Community mobility, Hand therapy, & Vision rehab. Typical entry-level training for an OT is to obtain a bachelor's degree and then complete two years of graduate-level academics and six months of clinical internships to obtain a master's degree.

Occupational Therapist Assistant (OTA)—A State-licensed clinician who works under the supervision of an OT to implement the occupational therapist's plan of care. Sometimes abbreviated as COTA, for Certified OTA, these clinicians are experienced in teaching, observing, and progressing the plan of care developed by the OT. Typical entry-level training for a COTA is two years of academics and two months of clinical internships to obtain an associate's degree.

Speech Therapist (ST)—Also known as a Speech Language Pathologist (SLP), is a State-licensed clinician who specializes in evaluating and treating disorders that result in difficulty speaking and/or difficulty swallowing (dysphagia). SLPs also assess cognition and help people to improve attention, memory, and problem-solving skills. STs create plans of care that include giving people exercises and activities to improve the quality of spoken language, facilitate the ability to communicate when speech, hearing, or auditory processing is impaired, and to optimize the ability to swallow foods and liquids without choking. Some STs have special training in the use of endoscopy and video fluoroscopy to assess vocal







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cord function and swallowing disorders. Typical entry-level training for an SLP is to obtain a bachelor's degree and then complete a two-year master's degree program, followed by a one-year clinical fellowship.

Speech Therapy Assistant (STA or SLPA)—is a State-licensed clinician who works under the supervision of an ST/SLP to implement the speech therapist's plan of care. These clinicians are experienced at teaching, observing, and progressing the plan of care developed by the speech language pathologist. Typical entry-level training for an SLPA is two years of academics with a concurrent clinical internship during the second year to obtain and associate's degree OR completion of a bachelor's degree in SLP.

Certified Personal Trainer (CPT)—is NOT a licensed clinician. These are fitness professionals who have completed a basic self-study certification in exercise science. In general, these professionals can create a fitness program, progress an exercise program, and assess a person to ensure they are completing exercises with proper technique and intensity. They can help implement an exercise program prescribed by a PT. However, they cannot assess and treat injuries, nor do they treat movement dysfunction.

WHAT CAN THERAPISTS DO FOR YOU?

PTs, PTAs, OTs, OTAs (lots of overlap):

Patient education, Caregiver training, Safe patient handling training, Exercise prescription, Assistive Device prescription, Adaptive Equipment prescription, Durable Medical Equipment (DME) prescription, Environmental Modification consultation, Functional Mobility training (bed mobility, transfers, transitioning movements), Strength training, Endurance training, Seating/Wheelchair assessment, Flexibility/Range of motion training, Joint mobilization, Tone management, Splinting/Bracing, Positioning, Edema management, Pain management, Balance training, Work hardening, Ergonomics assessment, Cognitive screening & training, etc.

PTs/PTAs:

Gait & Balance Training, Cardiopulmonary rehabilitation, Vestibular rehabilitation, Wound care

OTs/OTAs:

ADL re-training (dressing, hygiene, toileting, etc.), Vision rehabilitation, Driver re-training, Hand therapy

STs/SLPAs:

Speech assessment & training, Swallowing assessment & training, and Cognitive assessment & training

CPT*: (not medical clinician)

Fitness program creation and implementation



Physical Therapy Guidelines for Huntington's Disease

Background: Guidelines for physical therapy in Huntington's disease have recently been published (https://n.neurology.org/content/94/5/217). These guidelines are based on the best available research and give recommendations for treatments physical therapists should use to help people with Huntington's disease manage their problems with movement and daily activities.

Physical therapists use a variety of treatments to help people with Huntington's disease perform daily activities with the least amount of help from others. These treatments include education about staying active and how to safely exercise, teaching people to walk and balance better, showing people ways to prevent falls, and advising people about walking devices like canes/sticks and walkers and other equipment. Physical therapy and exercise are one part of the total care of a person with Huntington's disease, which may include treatment by other health professionals such as neurologists, psychiatrists, speech therapists, occupational therapists, counselors, and social workers.

Role of the Physical Therapist: The physical therapist will examine people's walking ability, posture, balance, muscle strength, and their ability to take care of themselves and their homes. Physical therapists conduct examinations to help understand why functional problems occur and to determine the best physical therapy treatments to meet peoples' unique needs.

When to Contact a Physical Therapist: We suggest that people with Huntington's disease see a physical therapist soon after they are diagnosed. This will allow the therapist to perform an evaluation and decide which physical therapy treatments best meet their current needs. Starting an exercise program soon after diagnosis will help people to move and balance better, and to be able to do their daily activities without help from others for as long as possible. The physical therapist can also help answer questions about how often to exercise as well as the type and amount of exercises. We recommend that people with Huntington's disease see a physical therapist every 6 months. However, if people with Huntington's disease have trouble walking, getting in and out of chairs or bed, or have stumbles or falls, they may need to see a physical therapist more frequently to reduce these problems.

Recommendations for Exercise and Physical Activity for people with Huntington's Disease: General Exercise Guidelines:

- a) Try to exercise at least three times a week for 20-30 minutes at a moderate intensity. Moderate intensity means that exercise should feel somewhat hard but not so hard that you cannot have a short conversation with someone. Your therapist can help you to determine the best specific exercises for you.
- b) Try to include exercise as part of your daily routine. Think about moving more and sitting less. Choose a time of day when you feel it is best to exercise. Choose the type of exercise that you like and that fits your physical abilities. Try to include several exercises in your routine. If possible, exercise with others as this may help to motivate you to keep exercising.

Specific Guidelines for Exercise:

- a) Doing moderate intensity aerobic exercise can improve your endurance and ability to move. Aerobic exercises include riding a stationary bicycle or an elliptical machine, going on a brisk walk or run, and walking or running on a treadmill.
- b) Strengthening and resistance exercises or circuit training (i.e., doing different exercises for a few minutes each) added to your exercise routine may help improve your ability to move.
 - Strengthening and resistance exercises may include exercise with resistance bands or weights, and doing exercises such as squats, lunges and step-ups as suggested by a physical therapist.
- c) Regular walking (with physical therapist help or done on own) may improve your ability to move.
- d) Practicing transfers (getting in and out of bed or in and out of a chair) may improve your ability get around.
- e) Breathing exercises may improve breathing function and coughing.

Guidelines for Mobility and Positioning Devices:

- a) For people who require help for walking, the physical therapist may suggest the use of a walker with four wheels (rollator walker) to make walking safer and to reduce the need for help from others.
- b) For people who don't have good posture while sitting, a physical therapist may suggest the use of special chairs to keep them in a good sitting posture.
- c) For people who don't have a good position in bed or while lying down, the use of positioning devices may be helpful.
 - Examples of positioning devices are wedge cushions, bolsters, pillows and bed railings for positioning in bed.
- d) For people who have muscle stiffness, stretching exercises may help to keep the joints moving through their full range of movement.

Guidelines for Late Stage Care:

- a) We suggest that each family keep in regular contact with their healthcare team to develop the best plan for care to meet the needs of people in the late stage of the disease.
- b) Doing activities that are enjoyable and involve family and friends may help to improve the mood, movement and well-being of people with Huntington's disease.
- c) Modifications to the home or surroundings and keeping good sitting posture are suggested to help people with Huntington's disease do their daily activities.

Clinical recommendations to guide physical therapy practice for Huntington disease. Lori Quinn, Deb Kegelmeyer, Anne Kloos, Ashwini K. Rao, Monica Busse, Nora E. Fritz Neurology Feb 2020, 94 (5) 217-228; DOI: 10.1212/WNL.0000000000008887



Exercise & Medical, Safety Equipment Resources

Lisa Mooney, LCSW

When seeking exercise advice or medical equipment, remember to consult your doctor for appropriateness and safety. Some medical equipment may be available through your health insurance and prescription from your doctor. Equipment that is not covered by your health insurance can always be purchased privately; costs will vary. Additional recommendations for medical equipment can be local consignment stores, Wal-Mart, Target and local churches. Please make sure that you inspect all medical equipment for proper maintenance and safety before using and/or purchasing. For a listing of local medical equipment providers in your area, please look in the yellow pages under Medical Equipment.



Exercise Resources





Medical Alert, Monitoring & Adaptive Resources

Medical Alert & Monitoring

Services include jewelry to wear to identify the person's medical needs, and device to call/monitor for assistance without phone. Examples:

LifeAlert, Medic Alert, Phillips Lifeline, etc.

Adaptive Equipment and Information

Assistive technology includes any device, software, or equipment that helps people work around their challenges. Some examples of assistive technology are text-to-speech and word prediction. Assistive technology includes low-tech tools, as well, like pencil grips.

Internet Search of Assistive/Adaptive Devices



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Finding Medical Equipment



Insurance Coverage

- Insurance will cover some medical equipment
- For information about what is covered, contact your insurance provider or visit: *U.S. Department* of Health & Human Services, Centers for Medicare & Medicaid Services



Speciality Equipment • Broda Chair (recliner)

- In Step Mobility (walkers)
- Motorized Wheelchairs, **Scooters**
- •These may not be covered by insurance, but can be found via internet search for options and costs.



- Carry equipment and other medical supplies
- Internet search for Medical Equipment or Supply Stores serving your area.



Where to find more information:







Contact your medical providers for assessment, recommendations and prescriptions as needed for insurance coverage.

Talk with other HD families. They can offer the resources, equipment and companies that worked or didn't work for them.

Contact HD Social Worker Lisa Mooney lkjer@hdsa.org 916.938-3576



Nutrition and HD

Lisa Kjer-Mooney, LCSW Kathryn Casey, NP

Over the course of HD, nutrition needs will change. Below are some of the common recommendations for maintaining proper nutrition throughout the disease. The information below is for information ONLY, please consult your HD team for recommendations that are specific to your medical needs.



Prodromal & Early Stage:

Heart healthy diet such as Mediterranean Diet

Maintain appropriate weight and BMI based on your gender, height, and age.

What is good for your

HEART is good for

your BRAIN

Exercise

Try to keep stress manageable

Limit alcohol, substances, and smoking these are brain toxins

Middle Stage: same recommendations as above, watch for swallow difficulties that can trigger increase in choking OR coughing when eating or drinking.

Use a straw when drinking liquids.

Keep track of foods that might trigger the coughing or choking and avoid or adapt to make swallowing easier.

For example: add moisture to dry foods, eat foods with more consistent/soft texture.

Watch for unintended weight loss and add calories or smaller, more frequent meals.

May experience loss of appetite, no enjoyment in eating, or forget to eat.

- Have easy to make or pre-made, ready to eat meals ready.
- Put timers in phone or house to remind when to eat.



<u>Late Stage</u>: same recommendations as above. Swallowing may get more difficult and may have increased weight loss due to not able to consume needed calories to maintain weight.

May benefit from nutritional supplements or support (Ensure, Boost, Feeding Tube) see below for more discussion on these recommendations

If losing weight, increase calories per meal (see below for ideas)

Consider soft, pureed foods to minimize swallow difficulties



Swallow Difficulties in Huntington's Disease

Swallowing difficulties can happen at any stage of HD and will increase in difficulty as the disease progresses. Difficulty swallowing also known as "dysphagia" is common in Huntington's disease. Food, liquids, or saliva can enter the throat resulting in coughing, choking, and over time aspiration pneumonia, dehydration, or weight loss.

Tucking the chin when swallowing



Tips for Swallowing Difficulties Using large straws and flexible straws for drinking

Eat slowly, minimize distractions (i.e. T.V., heavy discussion, etc.)

Take small bites and only take one bite of food at a time.

Assist the person with HD to eat and drink.

Sit upright at a 90degree angle to at least 45-degree angle for meals

Using commercial thickener in liquids to help make them easier to swallow

Alter food textures: eating soft foods, chopping, grinding, or puree depending on which texture is best for you. You may be referred to a speech therapist for swallowing evaluation and advice.

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Useful feeding tools to help with swallowing:

Blender or Food Processor for pureed/smoothies

Large handled utensils or Liftware (balance utensils) for better grip and feeding independence

High sided plates, divided plates to help scoop food onto utensil easier.

Cups with handles, built in straws, lids for better grip and minimize spilling.

Low flow cups – special cups that reduce the flow of liquid to minimize choking/coughing.

Assisting a Choking Adult: Anyone that eats food is at risk of choking. If needed, you can assist a person who is choking to dislodge the food item.

Step 1.

Determine if the person can speak or cough.

If not, proceed to the next step.



Step 2.
Perform an abdominal thrust (Heimlich Maneuver) repeatedly until the foreign body is expelled.



Step 3. A chest thrust may be used for markedly obese persons or in late stages of pregnancy.



If the adult or child becomes unresponsive perform CPR.

If you see an object in the throat or mouth, remove it.

Dehydration in Huntington's Disease: People with HD are at risk for dehydration, especially in warmer climates during the summer months. Our bodies are 60% water and need approximately eight glasses of water per day to maintain hydration. Bodily fluids are lost through sweating, breathing, urination, and bowels. Failure to replace these fluids can result in dehydration.

Why are people with HD more prone to dehydration?

Cognitive impairment can

alter a person's perception of thirst. People with HD who have difficulty organizing their thoughts and actions may be unaware they are thirsty, not remember to drink enough fluids, or express the need to drink.

Dysphagia (difficulty

swallowing) can also be a risk for dehydration. Many people with dysphagia need to have all their liquids thickened. Complex fluid preparation and fatigue can make it difficult to maintain an adequate fluid intake, especially if additional fluids

Motor impairment & chorea

may prevent some people from getting access to fluids. They cannot drink it if they are unable to get to it! Chorea can interfere with a person's ability to get a drinking container to their mouth. This can lead to frustration, which may cause the person to avoid drinking fluids.

Symptoms of dehydration:

Dry Mouth

Decreased urination or dark colored urine

Low blood pressure or fast heart rate

Change in mental status or confusion

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<u>Preventing dehydration:</u> Remember that a person with HD may not ask for fluids or tell you they are thirsty; therefore caregivers, family, and friends need to anticipate this need and plan accordingly

Have fluids within reach and remind to drink frequently: aim for 8oz every few hours, increase for persons in warm/home climates or those that sweat more.

Drinks with electrolytes are helpful if there has been vomitting, diarrhea, intense exercise or fever to maintain proper hydration.

During extreme heat, stay indoors, A/C preferably; if you must go outdoors, try to go in the morning, which is usually the coolest time

Always have fluids available when not at home (water bottles).

If there is concern about fluid intake, consider logging fluid intake: date, time & amount of fluid intake, daily should have 80-100oz and increase to 140+oz in hot climates.

Have cups with handles or water bottles with a spout or straw easily accessible.

When to seek medical attention for dehydration:

Change in mental status or confusion

Unable to drink by mouth

Unable to drink by mouth

Change in vital signs (increase heart rate, decreased blood pressure or temperature

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IDEAS to Increase Calorie Intake

Eat 4-6 smaller meals daily

Set a regular schedule for meals

Add high calorie snacks, nutritional drinks or shakes to increase calories and protein

Make shakes/smoothies, snacks in advance for easy grabbing

Shakes/smoothies in bulk & freeze in individual serving cups

Place 1-2 in refrigerator each night to be eaten the next day

High calorie foods:

- Oatmeal, hot cereal
- Cheese & cream cheese
- · Cream (heavy or whipping)
- Eggs
- Ice cream, yogurt, puddings
- Milk Powder- mix in with other foods to add calories and protein
- Oat Bran- can be mixed into food to increase calories and nutrients
- Nuts & nut butters- nuts can be finely ground and mixed into foods

- Salad dressing, mayonnaise, sour cream
- Sugars: honey, syrup, jam, frosting
- Whole milk
- Avocado
- Mashed sweet potatoes
- Gravies, sauces
- Hummus
- Oils: Coconut Oil, Avocado Oil, Olive Oil
- Mashed potatoes, macaroni and cheese, pastas, soft textured casseroles, beans, tofu,

Nutritional or Protein Supplements:

- Ensure or Boost
- Carnation Instant
- Protein Powder

- Muscle Milk
- Scandishake



Where to add extra calories

Shakes/Smoothies

- Use a blender, juicer, or food processor
- Add ice cream, fruit, oils, protein powder/nutritional drinks, nut butters, yogurt, ground chia or flax seeds, avocado, etc. for additional calories and protein.
- Choose flavors that the HD person enjoys.

Vegetables

- Add cheese, cream, sour cream, protein to mashed potatoes.
- Add cheese to vegetable sides (broccoli, asparagus, cauliflower, etc.)
- Add sauces (BBQ, ketchup, gravy, marinara sauce, pesto/alfredo, butter sauces, tahini, etc.)
- Choose flavors that the HD person enjoys.

Protein

- Add sauces to meat to add calories and add moisture to help with swallowing: (BBQ, ketchup, gravy, marinara sauce, pesto/alfredo, butter sauces, tahini, etc.)
- Choose flavors that the HD person enjoys.

Fruit

- Pair with yogurt, pudding for added calories.
- Pair with nut butters
- Add marshmallow, cream or yogurt sauce/dip.
- Choose fruits with soft texture to prevent swallowing difficulties



Community/Food Resources

Below are some community resources or businesses that you may want to consider in meeting your nutritional and food needs:

- Meals on Wheels (cooked meals delivered to those that qualify)
- Angel Food Ministries
- Food Banks

- Community Centers/Senior Centers
- Home Delivery Meals/Subscriptions
- Grocery Delivery

Help and support is available check out:

HDSA.org HDSA Center of Excellence HD Support Groups Help4HD

Area Agency on Aging (by County) Call 211 for info and resources in your area



Feeding Tube Facts for HD

Kathryn Casey, RN, FNP-C

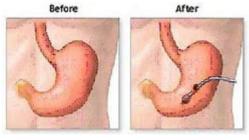
In the later stages of Huntington's some can have significant difficulty with swallow function and weight loss. Some choose to have a feeding tube placed to avoid choking, help provide adequate nutrition and fluids and take medications. The decision to have a feeding tube is very personal and should be discussed with your family and your HD care team. We advise that patients and families discuss this intervention early in the disease process when they have the ability to understand the advantages and disadvantages to feeding tubes.

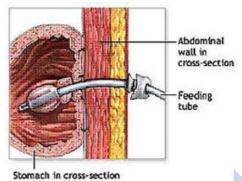
Feeding tubes do not need to be permanent; they can be removed when continued nutrition is no longer a goal of care such as near the end of life, and sometimes earlier if preferred.

Let's explore some of the what, when, who regarding feeding tubes. Remember, decisions may change as the disease progresses, therefore its most important to discuss your feelings, concerns and questions with your support team and medical care team.

WHAT is a feeding tube?

• It is a small, flexible tube inserted through the skin into the stomach, about ¼" in diameter that is an alternative route for nourishment and hydration.





WHEN to consider:

Noticeable weight loss, malnutrition, and frequent dehydration that cause concern or discomfort Swallowing difficulties preventing adequate eating and drinking to maintain health

When food or liquid going down into the lungs, (aspiration) is suspected.
Aspiration can put persons at higher risk for pneumonia

Meals are a struggle or frequent choking or gagging; no desire or energy to eat any longer





Feeding Tubes-- Advantages vs. Disadvantages



- May require replacement in the future, another procedure
- Small risk of infection at tube site

Surgical Procedure

- •Tube can get plugged or dislodged
- •Can be easily pulled out
- •Caregiving needed for cleaning, feedings and maintenance

Potential Side Effects

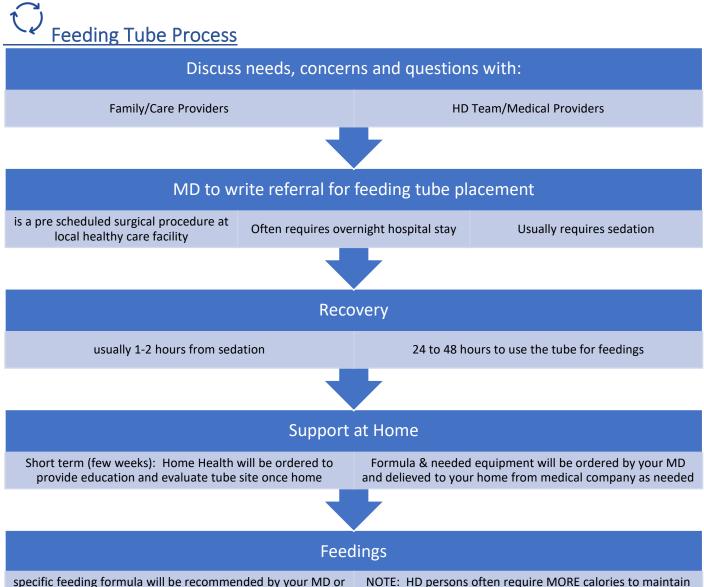
Frequently Asked Questions — Discuss all questions & concerns with your medical team.

Can I get Can feeding tube be Can you still eat medications through removed? with a feeding tube the feeding tube? Yes Yes Yes Many people will still eat Medications can be some food for comfort or Would be a medical admistered through the procedure, speak with pleasure as the feeding tube in liquid form, your medical team to tube is utilized to crushed & dissolved in discuss options maintain proper nutrition water to maintain health and life





registered dietician.



Adapted with permission from Theresa Imperato, RN from The ALS Association of Greater New York Chapter and Certified Center at Stony Brook. The UC Davis HDSA Center of Excellence thanks and acknowledges Theresa Imperato, RN and Lorraine Danowski, RD, from The ALS Association Greater New York Chapter and Certified Center at Stony Brook for this factsheet. Drawings by A.D.A.M.

Help and support is available check out:

HDSA Center of Excellence Medical Providers HDSA.org

weight than the average person

Speech Therapist Registered Dietician



HD Clinical Research Overview & Getting Involved

Rebecca Craig, MSHS & Talia Hamm, BA

Getting involved in clinical research is a personal decision. This guide is designed to provide you with the tools and information you need to make the most informed decision regarding study participation. This document is designed to help you understand what clinical research is, the types of research studies that may be available, some of the participation requirements, and your rights as a research participant. Any questions specific to a certain clinical research study such as age criteria, length of study visits, or compensation should be directed to study staff before agreeing to participate.

Clinical research IS NOT medical care. The main purpose of clinical research is to contribute to general scientific knowledge and NOT to guide your medical needs, even if your doctor and the researcher are the same person.

What is clinical research?

Clinical research is the study of health and illness in people. Clinical research studies teach us how to prevent, diagnose and treat illness. These studies help take laboratory research and translate it into new treatments and information to benefit patients. There are 2 main types of clinical studies:

Observational Research

- Does NOT include intervention or treatment option.
- Usually 1 visit per year over a set time period.
- Information and bio-specimens collected are centrally stored in repositories, which can be accessed by investigators worldwide. This helps speed up interventional trials and allows for researchers to make new discoveries without having to collect the data on their own.
- Observation Trials allow researchers to evaluate: Disease progression and progression rate; Patient symptoms; Disease markers provided by brain scans or blood tests, and other aspects of HD.

Interventional Research

- Commonly referred to as clinical trials
- Participants are given 1 or more new medical interventions.
- Used to evaluate the effects of these interventions on pre-defined outcome measures this may include Drugs, Devices, and/or Procedures
- These new interventions may be compared to:
 - An intervention that is already available
- Placebo (contains no active ingredients)
 - No intervention



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Methods of Interventional Research: Many factors can complicate clinical trials including bias on the part of the investigator or research subject. Here are some methods used to minimize bias:

Blinding

knowledge of the assigned treatment is hidden from one or more people involved with the study

Single-blind

 one party does not know assigned treatment. Usually this is the participant. This can also mean that the participant AND investigator are unaware of treatment assignment, which is a bit misleading

Double-blind

•The name is misleading. In double-blinded studies the participant, investigator, and study sponsor are all unaware of the treatment assignment

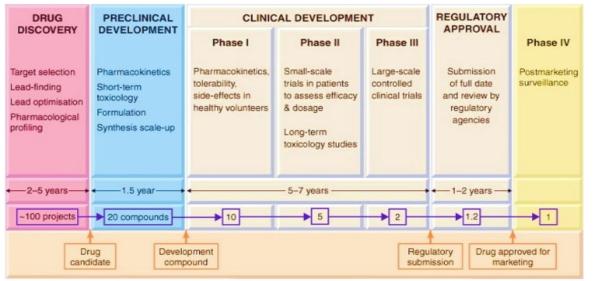
Triple-blind

•These studies are double-blinded AND the data analysis is done blinded

Randomization

- the study participant is assigned randomly to receive one of the study treatment assignments
- •Ensures each participant has an equal opportunity to receive the new intervention
- Equally distributes participant attributes amongst all treatment groups
- •Prevents investigators from choosing the "better" treatment for certain patients over others

Interventional (Clinical) Trial Phases to drug development:

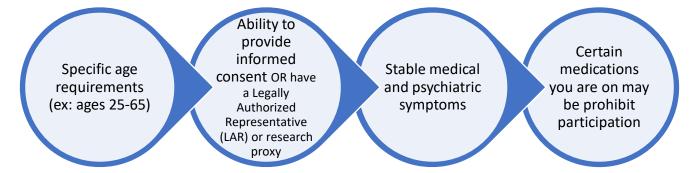


As you see, this process is long and not all products will make it to market. Getting and keeping study participants is essential to help move this process along as quickly as possible. That's where we hope YOU will come in!

Who can participate in research studies?

The study protocol is a research plan or roadmap designed to best answer the question posed by the study. The protocol includes criteria for who is eligible to maintain patient safety and to try to ensure the study sponsor can collect the data they need to answer their research question. Each study will have specific criteria, so while you may qualify for one study you may not qualify for another.

Inclusion criteria may include, but is not limited to:



For HD studies, researchers may wish to include people of a certain HD status such as all or some of the following groups:



How much time does clinical research require?



https://health.ucdavis.edu/huntingtons/

What happens during a clinical trial visit?

Informed Consent: Before any study procedures can take place, study staff will provide you with a consent form that details all the information about what it means to be a volunteer for the study, the criteria for participating in the study, and the possible risks and benefits associated with participating. It details what you can expect at study visits, how long the study will be, and all the contact information for study staff, the primary researchers, and the institutional review board for



any questions/issues during the study. After thoroughly reviewing the document and discussing all questions and concerns, you can decide whether you would like to proceed with participating in the study. Informed consent is a process that should continue throughout the study as you, as a voluntary research participant, have the right to withdraw consent at any point without negative consequences.



Study Procedures

Each study is different and exact study procedures will var. The exact procedures for each study is detailed in the informed consent. Some common study procedures include, but are not limited to the following:

- Vital signs: blood pressure, pulse, weight
- Discussion of medical history and current medications
- Evaluation of any health changes since the last study visit
- Physical and neurological exam
- Take blood samples (the amount of blood depends on the study)
- MRI imagining (depends on study)
- Study tasks (surveys and questionnaires)
- Cognitive assessments

Where will clinical research visits take place?

For clinical trials with the UC Davis HDSA Center of Excellence there are several locations where patients may be required to go, many located on the main hospital campus. The study staff will provide directions and parking information as needed for each study visit. On occasion, study visits can be scheduled concomitantly with clinic visits, which will take place off main campus at the UC Davis Health Midtown Neurology Clinic.



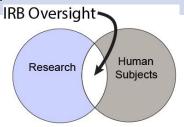
How are research participants protected?

Federal Agencies

- Protect rights and well-being of research participants
- In the United States the NIH and FDA oversee much of the medical research conducted.

Institutional Review Boards (IRB)

- consist of a combination of scientists and community members.
- They oversee research studies at the centers where clinical research takes place.
- NO research study can begin without review by the IRB.
- They ensure that the safety, rights, and well-being of research participants are protected.



Informed Consent

- What IS required for inclusion in the Informed Consent document is mandated by federal regulations
- It must include all necessary information for the participant to make a fully informed and voluntary decision on whether to participant or not.
- This process is ongoing and is reviewed often.

Confidentiality and Subject Rights' are prime concerns to researchers. Participant identities are known to study site personnel and select people who must oversee the study at each site. Participants are assigned a unique ID code at the time of enrollment, used for coding all study documents, blood samples and communication with parties outside the institution. Study staff will keep a document connecting the IDs with study participant name, but this document is only available to study staff. Despite these contingencies we can never 100% guarantee confidentiality and thus loss of confidentiality will always be listed as a risk of participation in clinical research. The California Experimental Subjects Bill of Rights is below and will be shared with you at the start of study participation.

Be informed of the nature and purpose of the experiment.

Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.

Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.

Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.

Be given a copy of the signed and dated written consent form.

Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.

Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation in the medical experiment without prejudice.

Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject's decision

Be informed of the avenues of medical treatment, if any, available to the subject after the experiment if complications should arise.

Be given an opportunity to ask any questions concerning the experiment or the procedures involved.

How is participating in clinical research different from seeing my doctor?

As discussed earlier, clinical research should never be confused with medical care even when the researcher and your doctor are the same person.

Participating in Clinical Research	Seeing Your Doctor
The researcher's goal is to learn about your illness and contributing to general scientific knowledge	Your doctor's goal is to treat your condition
The researcher must use standardized procedures. You may be removed from the study if your illness worsens	Your doctor will change your treatment as necessary and will see you even as your illness worsens
You will be randomly assigned to a group to take either:	Your doctor will usually offer standard treatment for your Illness and will be allowed to choose whatever standard treatment they think is best to treat you
The results from your participation may help researchers develop new treatments and may be published so that other researchers can learn	Your treatment is designed to help you, and not to help the doctor learn how to treat other people with your same illness
In some cases, costs of the study may be covered, and you may receive additional compensation	You will likely need to pay or use insurance for treatment
With your permission, researchers may check in with your doctors to learn about your conditions and past treatments	Your doctor usually won't share your information with researchers (In some cases, he or she may ask permission to share information)

Source: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health NIH Publication No. 09-4379 Reprinted 2009

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Who FUNDS research? Each study will have a specific funding source. Some examples of funding sources can include:



Do I get paid for research?

In order to avoid participants becoming involved in research for the compensation (this is called coercion) many studies will only reimburse participants for the costs they may incur to participate in the study. This can include reimbursement for travel, food expenses, etc. Reimbursement is study specific and will be detailed in the consent form.

Should participate in research?

There are reasons for and against participating in research. It will always depend on the individual and the nature of the research. If approached for study participation, it is important to ask any questions you may have about Participating with research staff.



Possible reasons to participate:

- You've always wanted to 'help'
- You want to contribute to the efforts for a cure/effective treatment
- You have time
- You care about HD research and future generations
- Being in research makes you feel like you are 'doing something' about HD



Possible reasons NOT to participate:

- •I don't have enough time due to other responsibilities
- •I'm concerned about my privacy
- •I prefer not to think about HD
- •I don't want to have physical exams or thinking tests
- •Fear of needles
- Not wanting to drive that far
- •I don't want to be on a placebo

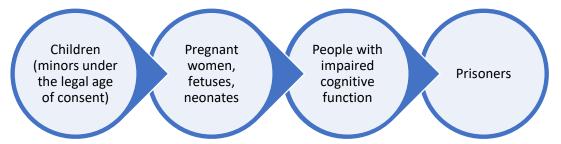


QUESTIONS about participating:

- •research is VOLUNTARY, you can change your mind at any time.
- You will not be treated differently or receive different care by NOT participating
- Contact UC Davis Research
 Coordinator, Becky Craig,
 rscraig@ucdavis.edu , Phone: 916-734-3541

Research and Vulnerable Populations

There are certain populations of participants which the federal regulations define as "vulnerable populations." These participants are groups of people who may require greater protection than normal as they may be at higher risk for negative outcomes, they may have reduced capacity to consent, they are more prone to coercion, etc. These groups include, but are not limited to:



Children and Research: Children and young adults can also volunteer to participate in research opportunities. As stated above, children are a protected population, meaning that IRBs require additional protections to be included in studies, to protect their wellbeing and safety as research volunteers.

Things to consider IF your child wants to participate in research:

- Children UNDER 18 years old will need agree to participate, AND
- Get one OR both parents or legal guardian permission for participation. The requirement of one or both parents will depend on the study.
- Research involving children and adolescents include a form called an ASSENT form. This
 provides information about study participation tailored specifically to participates
 age/development.
- ALWAYS, describe the study expectations to them in detail, at a level appropriate to their understanding.
- Children and adolescents interested in research participation should ask questions prior to deciding whether to participate. Parents/guardians should also ask questions, raise concerns prior to deciding to agree to participation.
- If a child turns 18 during a study, they will have to sign a consent form as an adult participant before continuing participation in the study.





Assent: Children cannot legally consent to research prior to the age of 18. In research that involves children under 18, they are asked to provide assent. Assent means that they agree to take part. They may also dissent, which means they do not agree. Unlike informed consent, assent is not always required by law, though <u>IRBs</u> may require it.

- To take part in the <u>assent process</u>, your child must be mature enough to understand the trial and what they are required to do.
- Some children as young as 7 years old may be able to take part. This age varies depending on the child and the group running the trial.

Blinding: also known as *masking*, this is the process of keeping the study group assignment hidden after allocation. Blinding is often used in research and is intended to help reduce the risk of bias in trials that have two or more study groups.

Clinical Research: clinical research examines people, or data or samples of tissue from people, which is studied to help understand health and disease processes. This type of research is intended to help find new and better ways to detect, diagnose, treat, and prevent disease.

Clinical Trial: A clinical trial is a type of study that where new medical approaches, such as new drug treatments or medical devices are examined to see how they work in people. Also called *clinical study*. There are four phases of clinical trials:

- <u>Phase I</u>: The main purpose of Phase I studies is to determine if the medical drug or device being studied is safe. Phase I trials have about 20-100 healthy volunteers and can take several months. This phase helps researchers assess how the drug or device effects humans (for example, in what way the human body absorbs, metabolizes and excretes the drug).
- <u>Phase II</u>: The main purpose of Phase II trials is to determine the efficacy of the drug or medical device. This phase may last several months or several years. There can be several hundred participants in Phase II trials, and most often phase II trials are randomized and include a control group.
- Phase III: Phase III drug studies are randomized and blinded studies, which can include hundreds to several thousands of participants. This phase can last several years and is intended to give the drug company and the FDA more information about how effective the drug or medical device is. This phase can last several years and helps drug companies and researchers clarify the benefits and possible adverse reactions of a drug.
- <u>Phase IV</u>: Phase IV trials are done after the drug is approved by the FDA for sale. In Phase IV trials drug companies may want to:
 - o compare a drug with other already available treatments
 - o monitor the efficacy of a drug over a period of time
 - determine the cost-effectiveness of a drug therapy as compared to already available treatments and/or therapies

Consent Form: A document with important information about a medical procedure or treatment, clinical trial, or genetic testing. It includes information on possible risks and benefits. If a person chooses to take part in the treatment, procedure, trial, or testing, he or she signs the form to give official consent. Even if a participant signs this document, they have the right to stop participating at any time they choose during the course of a study.

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Control Group: In a clinical trial, the control group is the group that does not receive the new treatment being studied. This is the group which is compared to the group that receives the new treatment. This is done to examine if the treatment is effective.

Double-Blind Study: A type of clinical trial in which neither the participants nor the researcher knows which treatment or intervention participants are receiving until the clinical trial is over. This makes results of the study less likely to be biased. This means that the results are less likely to be affected by factors that are not related to the treatment or intervention being tested.

Eligibility Criteria: Describe characteristics that must be shared by all participants. The criteria differ from study to study. Examples may include age, gender, medical history, and current health status.

Informed Consent: A process in which patients are given important information, including possible risks and benefits, about a medical procedure or treatment, genetic testing, or a clinical trial. This is to help them decide if they want to be treated, tested, or take part in the trial. Patients are also given any new information that might affect their decision to continue. Also called consent process.

Institutional Review Board: An institutional review board, often referred to as an IRB, is an administrative body created to protect the rights and welfare of human research subjects. Institutions typically have a local IRB which oversees any affiliated research activities. The IRB must review and approve all research involving human subjects, before any research activities can take place. In addition to approving the initiation of research with human subject, IRBs also review any proposed modifications to research activities. The IRB can approve, deny, request more information, or request changes to any proposed modifications submitted by researchers after the study is initially approved. IRBs are made of at least 5 members of diverse backgrounds to consider all possible consequences of the proposed research. IRBs include at least one member not affiliated with the institution, as well as one community member.

Interventional Study: An interventional study is one in which researchers administer and observe the effects of an intervention, such as a new medicine, in order to evaluate its efficacy and the effects. Clinical trials are a type of interventional study.

Observational Study: An observational study is one in which researchers observe the effect of a risk factor or disease, diagnostic test, treatment or other intervention without trying to change who is or is not exposed to it.

Placebo: A placebo is an inactive treatment. A placebo may be in a pill or tablet form, or it may be an injection or a medical device depending on the study. Placebos often look like the real medical treatment that is being studied except they do not contain the active medication. Placebos are used in clinical research to help scientists establish if a new treatment or medication is more beneficial that no treatment at all.

Principal Investigator: The principal investigator (PI) is the primary researcher for a given study. The PI is responsible for overseeing the entirety of the study including managing study staff and ensuring all activities adhere to the study protocol.

Sponsor: A person, company, institution, group, or organization that oversees or pays for a clinical trial and collects and analyzes the data.



Benefits: Financial & Insurance

Lisa Kjer-Mooney, LCSW

Below is an overview of the various financial and insurance benefits that you and your family may be eligible for and want to consider. If you are interested in any of these benefits or feel you may be eligible, please contact the administering agency of the program for more detailed information and/or the most current application. The following benefits are discussed:

Financial Benefits

- California State Disability Insurance (SDI)
- Social Security Disability Insurance (SSDI)
- California Paid Family Leave (PFL) Insurance Program
- Family Medical Leave Act (FMLA)

Insurance Benefits

- Medi-Cal
- Medicare
- Genetically Handicapped Persons Program (GHPP)
- California Children's Services (CCS)
- Covered California
- COBRA
- Long Term Care Insurance

TIPS for Application Processes: Please be aware that with any application process it can be slow

and somewhat frustrating

Be sure to complete the application forms completely and submit all necessary supporting documentation (financial statements, medical records, etc.) to avoid processing delays.

Always ask for assistance when you have questions.

When working with government agencies remember to be thorough, organized and patient.

If you are denied SDI, SSDI, Medi-Cal, GHPP or CCS you do have the **right to appeal the decision**. With some of these programs you may be denied initially, however after the appeal process you may be approved.



\$

Benefits: FEDERAL GOVERNMENT

Social Security Disability Insurance (SSDI)

Overview: federally funded administered through the Social Security Administration. SSDI provides benefits to disabled or blind individuals who have worked for an employer(s) that have contributed to the Social Security trust fund.

Benefits: Paid compensation for inability to participate in gainful employment due to long term disability.

Eligibility:

- Must have worked and paid Social Security taxes for 10 years; 5 of the 10 years must be in last 5 years.
- Must meet the definition of "medically disabled".
- Complete necessary claim application
- Not be working or working but not performing substantial gainful activity

For more information you may contact:

- Social Security Administration
 - On-line or Telephone at 1-800-772-1213
 - Visit local social security office

Supplemental Security Income (SSI)

Overview: Supplemental Security Income (SSI) is federally funded administered through the Social Security Administration.

Benefits: SSI provides cash assistance payments to aged, blind and disabled individuals who have limited income and resources.

Eligibility for SSI based on disability:

- Have limited income and resources.
- Be a U.S. citizen and reside in the 50 States,
 District of Columbia or Northern Mariana
 Islands
- Meet definition of medically disabled or blind
- Complete necessary claim application
- File for any and all other benefits for which you are eligible
- Not be working or working but not performing substantial gainful activity

For more information you may contact:

- Social Security Administration
 - On-line or Telephone at 1-800-772-1213 or local social security office

Family Medical Leave Act (FMLA) of 1993 - protects your job, does not provide income

Overview: administered through the U.S. Department of Labor's Employment Standards Administration, Wage and Hour Division. FMLA applies to all public agencies, including state, local and federal employers, schools and private-sector employers who employ 50 or more employees.

Benefit: FMLA offers eligible employees to take up to **12 work weeks of UNPAID** time off during a 12-month period for specific family and medical reasons:

- to take medical leave for yourself if you are unable to work due to serious health condition
- to care for spouse, son, daughter or parent with serious health condition
- the birth and care of a newborn child

Eligibility:

- must work for a covered employer
- have worked for your employer for a total of 12 months
- have worked at least 1,250 hours over the previous 12 months

For more information you may contact:

- Your employers human resource office
 - U.S. Department of Labor, Wage and Hour Division -- On-line or Telephone at 1-866-487-9243



Benefits: STATE (CA) GOVERNMENT

California State Disability Insurance (SDI)

Overview: administered through the California Employment Development Department (EDD). SDI provides temporary benefit payments to workers for non-work-related disabilities.

Benefits: Paid compensation for wages lost due to disability. Benefit amount is based on a percentage of your earnings. Disability is payable for a maximum of 52 weeks. **Eligibility:**

- Must have been employed prior to disability and paying into SDI
- You must be unable to do your regular or customary work for at least eight consecutive days
- Complete necessary claim application
- Complete doctor's certification
- Other eligibility requirements may apply

For more information you may contact:

- Employment Development Department (EDD)
 - o On-line EDD.gov or Telephone at 1-800-480-3287
- · Your employers' human resources office

California Paid Family Leave (PFL) Insurance Program

Overview: administered through the California PFL provides eligible workers to take paid time off to care for parents, children, spouses and registered domestic partners or to bond with a new minor child.

Benefit: Offers up to 6 weeks of leave in a 12-month period for employees who are covered by State Disability Insurance. Provides benefits of approximately 55% of lost wages. This program does <u>not</u> provide job protection or return rights as the Family Medical Leave Act does.

Eligibility:

- Must be covered by State Disability Insurance.
- Complete necessary application and claim forms
- Supply medical information to support claim
- May need to use any earned but unused paid time off, vacation or sick leave prior to receiving benefits
- Other eligibility requirements may apply

For more information you may contact:

- Your employers human resource office
 - Employment Development Department (EDD)-- On-Line or Telephone at 1-877-238-4373

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Insurance Benefits – Government

Medi-Cal

Overview: administered through the Department of Health Care Services. Provides health care for low-income individuals.

Benefit: assist with costs associated with hospitalizations, doctor visits, labs, x-rays, physical, speech and occupational therapy, medically necessary medical equipment, short term skilled nursing care and short term in home skilled nursing care (home health). Medi-Cal covers some long-term custodial care services such as:

 In-Home Support Services (IHSS) or Long-Term Care Skilled Placement

Eligibility:

- based on income & may have monthly share of cost.
- 65 or older; Blind; Disabled; Under 21; Pregnant
- Persons residing in skilled nursing home
- Resident of California

For more information you may contact:

 Department of Health Care Services -- Online; Telephone at 916-552-9200

Medicare

Overview: federally funded medical insurance for persons aged 65 and older OR persons receiving Social Security Disability Insurance.

Benefit:

- Part A covers hospitalizations and hospice and short term (100 days or less) in skilled nursing care or rehabilitation
- Part B covers costs associated with medical care received in an outpatient environment when medically necessary. Part B in most cases has a monthly premium. Enrolling in Medicare Part B is optional.
- Part D assists with the costs of prescription medication.
- Medicare Advantage Plans administered through (HMO or PPO) private insurance companies that can offer additional coverage.

Eligibility:

- Paid into Social Security for at least 10 years.
- 65 or older
- Resident of United States
- Receiving Social Security Disability Insurance for at least 2 years

For more information you may contact:

 Social Security Administration -- On-line or Telephone at 1-800-772-1213

Genetically Handicapped Persons Program (GHPP)

Overview: State funded insurance program administered by the Department of Health Care Services to pay for medical costs for persons with genetic medical conditions, of which Huntington's Disease is a covered disease. **Benefit:**

- cover medical costs including hospitalizations, doctor visits, x-ray, laboratory, surgery, prescriptions, physical therapy, occupational therapy, psychosocial services, dental, speech therapy, nutrition products and medical food and medical equipment/supplies.
- There may be an annual enrollment fee depending on family size and income.

Eligibility:

- 21 years of age or older (if under 21 apply for California Children's Services (CCS)
- Resident of California
- Qualifying medical condition
- Complete application includes financial information & medical records verifying HD or HD risk.

For more information you may contact:

o Department of Health Care Services -- Online or Telephone at 1-800-639-0597 or (916) 327-0470

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Insurance Benefits – Government (cont.)

California Children's Services (CCS)

Overview: State funded program administered by the Department of Health Care Services for **children** with certain diseases or health problems. HD is an eligible genetic medical condition.

Benefit: cover medical costs including hospitalizations, doctor visits, x-ray, laboratory, surgery, physical therapy, occupational therapy, and medical equipment/supplies.

Eligibility:

- under 21 years old
- has or may have a medical condition that is covered by CCS
- Resident of California
- has a family income of less than \$40,000 or whose out-of-pocket medical expenses for a child who qualifies are expected to be more than 20% of family income; or the child has Healthy Families coverage.

For more information you may contact:

Department of Health Care Services

Covered California

Overview: Part of Affordable Care Act, Covered California is a program where individuals/families can compare quality health plans and choose a coverage plan that works best for their health needs and budget.

Benefit: Health insurance coverage for all family members regardless of past health history. Covered California has four standard benefit levels: Bronze, Silver, Gold and Platinum to meet the various needs of the family's expected use of medical services.

Eligibility:

- Qualified legal California residents
- Costs based on coverage plan selected, family size, county of residence and income.

For more information you may contact:

- California Health Benefit Exchange --On-line at <u>www.CoveredCA.com</u>; Telephone: 1-800-300-1506
- Covered California Certified Educator, Enrollment Counselor or Insurance Agency is available, please visit website to locate these services.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

Overview: health benefit passed by congress in 1986. Provides continuation of group health coverage that otherwise might be terminated with loss of employment, etc.

Benefits: provides former employees, retirees, spouses, former spouses, and dependent children the right to temporary continuation of health coverage at group rates. COBRA health benefits can extend employer linked medical insurance for 12-18 months up to 36 months. You will be pay 102% of the group premium for your health plan.

Eligibility:

- You must have been enrolled in your employer's health plan when you worked, and the health plan must continue to be in effect for active employees.
 - COBRA continuation coverage is available upon the occurrence of a qualifying event that would cause an individual to lose his or her health care coverage: Laid off; Disability; Extended Leave of absence; Voluntary termination of employment

For more information you may contact:

- Your employers human resource office
 - U.S. Department of Labor, Employee Benefits Security Administration online or Telephone at 1-866-444-3272



Benefits – Private Pay Supplement Insurance

Long Term Care Insurance

Overview: can cover a variety of services NOT COVERED by medical insurance such as in-home assistance or out of home placement.

- must be purchased separately from other health care insurance.
- should be purchased early and prior to any illness or injury.

Benefit: LTC insurance policies vary, however can cover services such as:

- in-home care to assist with daily living activities (bathing, dressing, cleaning, cooking, etc)
- assisted living facilities
- nursing home care
- community services
 - Adult Day Health Care
 - Respite Care

Eligibility:

- Depends on company and policy
- Employers are beginning to offer LTC insurance as part of employer benefits packages
- Pre-existing health conditions may disqualify you

For more information you may contact:

 Health Insurance Counseling and Advocacy Program (HICAP) - On-line or Telephone at 1-800-434-0222

More information is available:

HDSA.org HDSA Center of Excellence UC Davis

EDD SSA



How to File for Social Security Disability What you need to know

Lisa Mooney, LCSW

As of 2012, 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 HD persons, however, don't apply to soon, you will need to ensure that there is enough medical evidence to meet the definition of disability under Social Security law.

Ways to Apply:

On-line www.ssa.gov **Telephone**

1-800-772-1213

In person

local Social Security Office (see website for closest office to you)

Eligibility:

You have to have paid into the SSA system for at least 40 quarters (10 years)

You must have worked at least 20 quarters (5 years) in the last 40 quarters (10 years).



What you want to PROVE:

You have the disease by either medical & family history or genetic testing results, AND

Demonstrate <u>how symptoms</u> prevent you from working.

Symptoms can include movements, physical impairments/limitations, cognitive difficulties and behavioral & emotional symptoms.

If you did not pay into the system for 40 quarters or have been self-employed or not working, you may be eligible for Supplemental Security Income (SSI). Visit the Social Security Website for more information.



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What you will need for the application:

Compassionate Allowance Listing Designation

When entering your disability state:

"Huntington's Disease with increasing limitations under DI 23022.923" OR "Juvenile Huntington's Disease under DI 23022.923 or Early-Onset HD under DI 23022.923"

When an application is flagged in the system as Compassionate Allowance, it should not ask lengthy questions about past employment history.

Documentation

- 1. Medical
- 2. Employment
- 3. Personal and Family Observations

Medical Documentation

- •Names, addresses and telephone numbers of doctors, hospitals, clinics, and institutions that treated you and dates of treatment.
- Medical records from General Practitioner/Primary Care Physician, Neurologist, Psychiatrist/Psychologist, Genetic Counselor, Nurse Practitioner, etc. that demonstrates that you have HD symptoms AND details what those symptoms are. Physician and Nurse Practitioner are weigted more in the review process.
- •Include a list of the medications you are taking
- Medical Exams like United Huntington's Disease Rating Scale (UHDRS), UHDRS Total Functional Capacity, Montreal Cognitive Assessment (MOCA), Mini Mental Status Exam, NeuroPsychological Testing, Tinetti Mobility Exam, Swallow Studies, etc can all support your claim.

Employment Documentation

- Employment records that demonstrate a decline in performance or work place accommodations you had due to not meeting expectations. This can include: e-mails, formal disciplinary action or write ups.
- •if only verbal meetings were held to discuss your work performance, you can include the date, time, staff/supervisors present and details of the discussion in your journal to submit with your application.
- •work history over past 16 years: Company names, addresses and telephone numbers along with description of the kind of work you did

Personal and Family Documentation

Keep an "Activities of Daily Living" journal: describe how HD symptoms are preventing you from completing everyday tasks such as cooking, cleaning, paying bills, driving, managing medication, dressing, bathing, housekeeping, caring for children, etc.

- •It may be best for FAMILY MEMBERS to keep the diary as they can often see subtle changes that may be happening. OR including letters from family/friends that can demonstrate how you have changed over time and what you are not longer able to do independently
- •Keep the journal as matter of fact as possible and SUMMERIZE the symptoms/changes caused by HD.
- •Submit the journal with your application.
- •You will need to have your Social Security number for you, spouse and minor children for the application.

Tel: 916-734-6277



Medical Disability Definition - as defined and evaluated by Social Security

The inability to engage in any substantial gainful activity (SGA) because of medically determinable physical or mental impairment(s):

That can be expected to result in death, OR

That has lasted or that we can expect to last for a continuous period of not less than 12 months.

Medical Disability Evaluation Criteria: The Social Security process for to determine disability involves 5 steps:

Can you do any other type of

work?

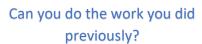
If unable to do your previous work SS evaluates your age, education, past work experience and transferable skills to determine if you can work in another type of iob.

Are you working?

If you are working and your Monthly INCOME cannot exceed the SGA level (around \$1200) you will likely not be considered disabled.

Is your medical condition "severe"?

To qualify your impairment(s) must significantly limit your ability to do basic work activities (walking, sitting, seeing and remembering)



SS is evaluating to determine if your impairment prevents you from performing the duties of your current/previous job.

Is your medical condition in the list of disabling impairments?

HD is on the Compassionate Allowance List, see following page "Impairment Evaluation Criteria" for the specific details of what social security is looking for in the application.



HD diagnosis is not enough to be considered disabled. Social Security is evaluating your functional

ability as it relates to your ability to work and care for yourself.

Language Do's & Don'ts:

DO Say	DON'T SAY
 I am limited by balance from doing any work around dangerous machinery, etc I am off task more than 10% of my time at work Due to my illness I miss work more than 2x per 	• I can't work
 month. I have troubles with fine motor making difficult and unsafe. 	I am totally disabled
 As a result of HD symptoms I am experiencing impulsivity which is causing difficulties in getting along with co-workers and customers. 	I should be awarded benefits
 I am limited by cognitive decline and I am unable to learn new tasks and take on new responsibilities. Inability to retain story line in a 2 hour movie, 1 hour show or even 30 minute show Unable to retain/follow story in book or magazine. 	NONE of the "Don't Say" column tells the assessor what is happening with you and this information will cause the application to be denied.

Who decides if you are disabled?

Completed applications are sent to the **Disability Determination** Services (DDS) offices in California.

The DDS office team consists of a physician or psychologist and a disability examiner

They will use the medical evidence you submit to make a final decision.

Submitting the Application and Approval/Denial:

Keep copies of everything you submit to SSA.

If you are referred to a DDS medical consult, you can request to by evaluated by your MD and SSA has to allow that.

If denied, you have the opportunity to appeal within 60 days.

FOR MORE INFORMATION VISIT:



Evaluation Criteria from SSA please visit:

https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm Click on Sec 11.00, Neurological Disorders, and scroll down to 11.17 or 12.00 Mental Disorders, scroll to 12.02 NeuroCognitive Disorder





Impairment Evaluation Criteria

Huntington's disease is on the Compassionate Allowance List and falls under the following section:

- Section 11.00 Neurological Disorders
 - 11.17 Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration.
 - If not diagnosed as having clinical HD, can consider disorders in 12.00 Mental Disorders
 - 12.02 Neurocognitive Disorders

When evaluating your disability claim, Social Security will be looking for evidence of the following impairment(s):

Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

OR

- Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following:
 - 1.Understanding, remembering, or applying information (see 11.00G3b(i)); or
 - 2.Interacting with others (see 11.00G3b(ii)); or
 - 3. Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or
 - 4. Adapting or managing oneself (see 11.00G3b(iv)).

OR

- Medical documentation of a significant cognitive decline from a prior level of functioning in one or more of the cognitive areas:
 - Complex attention;
 - Executive function;
 - Learning and memory;
 - Language;
 - Perceptual-motor; or
 - Social cognition.

AND

- Extreme limitation of one, or marked limitation of two, of the following areas of mental functioning (see 12.00F):
 - Understand, remember, or apply information (see 12.00E1).
 - Interact with others (see 12.00E2).
 - Concentrate, persist, or maintain pace (see 12.00E3).

Adapt or manage oneself (see 12.00E4).

OR

- Your mental disorder in this listing category is "serious and persistent;" that is, you have a medically documented history of the existence of the disorder over a period of at least 2 years, and there is evidence of both:
 - Medical treatment, mental health therapy, psychosocial support(s), or a highly structured setting(s) that is ongoing and that diminishes the symptoms and signs of your mental disorder (see 12.00G2b); and
 - Marginal adjustment, that is, you have minimal capacity to adapt to changes in your environment or to demands that are not already part of your daily life (see 12.00G2c).



Motor Functioning is defined as:

- What does SSA mean by disorganization of motor function? From: https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11 17
 - Disorganization of motor function means interference, due to your neurological disorder, with movement of two extremities; i.e., the lower extremities, or upper extremities (including fingers, wrists, hands, arms, and shoulders). By two extremities we mean both lower extremities, and both upper extremities, or one upper extremity and one lower extremity. All listings in this body system include criteria for disorganization of motor function that results in an extreme limitation in your ability to:
 - 1. Stand up from a seated position; or
 - 2. Balance while standing or walking; or
 - 3. Use the upper extremities (including fingers, wrists, hands, arms, and shoulders).
 - Need to demonstrate through your documentation the degree of interference with your ability to move and ambulate and/or interference with the use of fingers, hands and arms in your work environment and at home when taking care of yourself.



Mental Functioning Changes is defined as:

How does SSA evaluate limitations in physical and mental functioning under these listings? Excerpts from: https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11 17

- Marked Limitation in one of the four areas of mental functioning (see 11.00G3). The term
 "marked" does not require that you must be confined to bed, hospitalized, or in a nursing home.
 - Marked limitation and physical functioning means that, due to the signs and symptoms of your neurological disorder, you are seriously limited in the ability to:
 - o Independently initiate, sustain, and complete work-related physical activities.
 - you may have a marked limitation in your physical functioning when your neurological disease process causes persistent or intermittent symptoms that affect your abilities to independently initiate, sustain, and complete work-related activities, such as standing, balancing, walking, using both upper extremities for fine and gross movements, or results in limitations in using one upper and one lower extremity.

- The persistent and intermittent symptoms must result in a serious limitation in your ability to do a task or activity on a sustained basis.
- You need not be totally precluded from performing a function or activity to have a marked limitation, as long as the degree of limitation seriously limits your ability to independently initiate, sustain, and complete work-related physical activities.
- Marked limitation and mental functioning due to the signs and symptoms of your
 <u>neurological disorder</u>, you are seriously limited in the ability to function independently,
 appropriately, effectively, and on a sustained basis in work settings.
 - We do not define "marked" by a specific number of mental activities, such as: the number of activities that demonstrate your ability to understand, remember, and apply information; the number of tasks that demonstrate your ability to interact with others; a specific number of tasks that demonstrate you are able to concentrate, persist or maintain pace; or a specific number of tasks that demonstrate you are able to manage yourself.
 - You may have a marked limitation in your mental functioning when several activities or functions are impaired, or even when only one is impaired.
 - You need not be totally precluded from performing an activity to have a marked limitation, as long as the degree of limitation seriously limits your ability to function independently, appropriately, and effectively on a sustained basis, and complete work-related mental activities.

• Areas of physical and mental functioning.

- Physical functioning. Examples of this criterion include specific motor abilities, such as independently initiating, sustaining, and completing the following activities: standing up from a seated position, balancing while standing or walking, or using both your upper extremities for fine and gross movements Physical functioning may also include functions of the body that support motor abilities, such as the abilities to see, breathe, and swallow.
- Mental functioning.
 - Understanding, remembering, or applying information. This area of mental functioning refers to the abilities to learn, recall, and use information to perform work activities. Examples include: understanding and learning terms, instructions, procedures; following one- or two-step oral instructions to carry out a task; describing work activity to someone else; asking and answering questions and providing explanations; recognizing a mistake and correcting it; identifying and solving problems; sequencing multi-step activities; and using reason and judgment to make work-related decisions. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.
 - <u>Interacting with others.</u> This area of mental functioning refers to the abilities to relate to and work with supervisors, co-workers, and the public. Examples include: cooperating with others; asking for help when needed; handling conflicts with others; stating your own point of view; initiating or sustaining conversation;

understanding and responding to social cues (physical, verbal, emotional); responding to requests, suggestions, criticism, correction, and challenges; and keeping social interactions free of excessive irritability, sensitivity, argumentativeness, or suspiciousness. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.

- Concentrating, persisting, or maintaining pace. This area of mental functioning refers to the abilities to focus attention on work activities and to stay on-task at a sustained rate. Examples include: initiating and performing a task that you understand and know how to do; working at an appropriate and consistent pace; completing tasks in a timely manner; ignoring or avoiding distractions while working; changing activities or work settings without being disruptive; working close to or with others without interrupting or distracting them; sustaining an ordinary routine and regular attendance at work; and working a full day without needing more than the allotted number or length of rest periods during the day. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.
- Adapting or managing oneself. This area of mental functioning refers to the abilities to regulate emotions, control behavior, and maintain well-being in a work setting. Examples include: responding to demands; adapting to changes; managing your psychologically based symptoms; distinguishing between acceptable and unacceptable work performance; setting realistic goals; making plans for yourself independently of others; maintaining personal hygiene and attire appropriate to a work setting; and being aware of normal hazards and taking appropriate precautions. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.
- Make sure to demonstrate the change in mental functioning in the above areas with specific examples/incidents and/or any written documentation from an employer or medical professional that illustrates the decline in mental or physical functioning and the impact it has on the person's ability to meet employer expectations and perform the duties of their job.

Do I need a lawyer and how do I find a lawyer:

Technically you do not need a lawyer to apply for disability. If you or your family is thorough and completes the application and provides the necessary documentation discussed above, you should NOT need a lawyer. If your application is denied and you completed all the steps/recommendations above, you may wish to consult your HD care team for advice and seek attorney if you feel necessary. Most families navigated this process successful without an attorney, it can be stressful and you may have to appeal an initial denial but does not require attorney involvement unless you want it.

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Tel: 916-734-6277

<u>Finding A Lawyer:</u> Social Security is a FEDERAL program; therefore you can have an attorney licensed in any state represent you.

National Organization of Social Security Claimants' Representatives (NOSSCR)

•https://nosscr.org/referral-service/ These attorney's specialize in representing families through Social Security disability claims (may not assist with initial applications, services may be after a denial). They will charge a fee - generally portion of back pay.

Allsup

• https://www.allsup.com/; this is an organization that helps families with the disability process starting at the initial application level. You will have to go through a vetting process to determine if Allsup will take your case. They will charge a fee - generally portion of back pay

Employee Assistance Program (EAP) •If a family member or spouse is still working, their employer (50+ more employees) likely has an Employee Assistance Program (EAP) in which legal assistance is a benefit. This is a avenue to connect with a lawyer and ask some questions. There will be a cap/limit on the number of hours or visits available, however if you liked the attorney you can continue to pay for it out of pocket.

Personal Referrals

•word of mouth from others that have utilized an attorney in the past is a good way to find an attorney that you feel comfortable working with assuming you trust your friend/family did their due dilligance to ensure the attorney was in good standing with Bar Association.

County Bar resource listings, State Bar (Calbar.ca.gov) listings

•You can often do a search at county or state Bar Association websites to find attorney's that are licensed and in good standing.

Additional Help and support is available

HDSA.org Social Security Administration Special Needs Alliance

Disability Rights California

Information shared in this document is from www.ssa.gov: Social Security Red Book and Social Security Blue Book, List of Impairments, as well as disability tips shared by Allison Bartlett, Esq, Manager of Disability Programs @ HDSA.



How to File for Social Security Supplemental Security Income – Adults and Children

Lisa Mooney, LCSW

Supplement Security Income (SSI) is a benefit that children and adults may qualify for if they are 1) disabled, and 2) have limited resources. SSI is available for those persons that due to disability were unable to be employed and pay into the Social Security system through employment or are a minor that is disabled and has financial need. As of 2012, Adult on-set Huntington's Disease (HD) and Juvenile Onset Huntington's Disease (JoHD) were both added to the Social Security Administration's Compassionate Allowance List (CAL). This means applications under the SSI programs will be expedited for HD persons, however, don't apply to soon, you will need to ensure that there is enough medical evidence to meet the definition of disability under Social Security law.

Ways to Apply:

On-line www.ssa.gov **Telephone** 1-800-772-1213

In person

local Social Security Office (see website for closest office to you)

Eligibility:

Disabled, AND

Limited resources/low income

 This can be confusing for minors as FAMILY resources are considered to determine eligibility, its hard to get a clear "limit" as they base it on family size, number of minors in family. Good rule of thumb is to call SS to discuss your family particulars.



What you want to PROVE:

You have the disease by medical & family history or genetic testing results, AND

Demonstrate **how**

symptoms impact abilities or day to day functioning of age appropriate tasks:

Dressing, bathing, brushing teeth, using phone, walking/running, school performance (at grade level or below), etc.

Provide

documentation of "limited resources. Listed in the following pages are what "resources" are considered by SSA to make this determination.

Minors (18 and

younger), parents (those living IN the home, biological or step)/household resources & income ARE considered when determining eligibility for SSI.

Adults (18 or over), do NOT report household resources/income and are evaluated on ability to WORK.





What you will need for the application:

Compassionate Allowance Listing Designation

Disabling Condition:

"Huntington's Disease with increasing limitations under DI 23022.923" OR "Juvenile onset Huntington's Disease under DI 23022.923."

Medical Documentation

- Names, addresses and telephone numbers of doctors, hospitals, clinics, and institutions that treated you or the minor and dates of treatment.
- Medical records from General Practitioner/Primary Care Physician, Neurologist, Psychiatrist/Psychologist. Genetic Counselor, etc. that demonstrates that you have HD symptoms AND details what those symptoms
- •Include a list of the medications you or minor are taking

Employment Documentation OR School Records (for Minors)

- •Employment records (if any) that demonstrate inability for you to maintain employment expectations. This can include: e-mails, formal disciplinary action or write ups.
- Employment history or employment attempts since disability: Company names, addresses and telephone numbers along with description of the kind of work you did
- •School Records: testing, IEP/School accomodations implemented for the student. Teacher feedback, assessments, e-mails on abilities, educational performance, report cards,

Personal and Family Documentation for ADULTS

ADULTS: Keep an "Activities of Daily Living" journal: describe how HD symptoms are preventing you from completing everyday tasks such as cooking, cleaning, paying bills, driving, managing medication, dressing, bathing, housekeeping, caring for children, etc.

- •It may be best for FAMILY MEMBERS to keep the diary as they can often see subtle changes that may be
- •Keep the journal as matter of fact as possible and SUMMERIZE the symptoms/changes caused by HD.
- •Submit the journal with your application.
- •You will need to have your Social Security number for you, spouse and minor children for the application.

Family Documentation for MINORS

MINORS: Parents/guardians -- Keep Journal of your child's decline in physical, emotional or cognitive abilities (changes in school participation, sports abilities, interaction with peers, comparison of their abilities to other kids their age, loss or change in developmental milestones.)

- •Keep the journal as matter of fact as possible and SUMMERIZE the symptoms/changes caused by JoHD.
- •Submit the journal with your application./



What INCOME is considered in eligibility

Please visit https://www.ssa.gov/ssi/text-income-ussi.htm to get the full extensive list of "income" from Social Security.

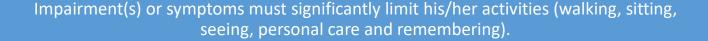
NOTE: for those applying for *SSI for minors* (those under 18), Social Security WILL consider household/family income for eligibility this will include biological and step parents. In some cases a minor MAY qualify for SSI and SSI will reduce the amount received based on the household/family countable income. For more specifics on what family/household income is counted please visit the https://www.ssa.gov/ssi/spotlights/spot-deeming.htm. (Note: parent pension/retirement is NOT counted and In Home Support Services is also EXCLUDED from the household income.)

Remember, Any minor (under 18) receiving SSI will be re-evaluated at age 18. At that time, they are considered a legal adult and therefore are evaluated on their ability to work or not work and household income will NOT be considered. Please explore getting conservatorship/guardianship for your HD loved one as Social Security will consider persons over 18 an adult and thus will need written documentation or verbal consent to speak with another person regarding their social security claim. Social Security does have Form 1696 Appointment of Representative that can be completed as well.



Medical Disability Evaluation Criteria & Who Decides: The Social Security process for to determine disability involves proving:





Completed applications are sent to the Disability Determination Services (DDS) offices in the State you reside. (Length of time for processing depends on each State -- some are faster than others)

The DDS office team consists of a physician or psychologist and a disability examiner

They will use the medical evidence you submit to make a final decision.



Submitting the Application and Approval/Denial:

Keep copies of everything you submit to SSA.

If you are referred to a DDS medical consult, you can request to by evaluated by your MD and SSA has to allow that.

If denied, you have the opportunity to appeal within 60 days.



TIPS to consider when applying



HD or JoHD diagnosis is not enough to be considered disabled. Social Security is

evaluating the applicants functional ability as it relates to the ability to work and/or care for him/herself at age appropriate level.

Language Do's & Don'ts:

DO Say	DON'T SAY
 I am limited by balance from doing any work around dangerous machinery, etc Unable to lift more than 25 lbs safely Unable to walk or navigate stairs while carrying items. 	• I can't work
 I have troubles with fine motor making difficult and unsafe. 	I am totally disabled
 As a result of HD symptoms I am experiencing impulsivity which is causing difficulties in getting along with co-workers and customers. 	I should be awarded benefits
 I am limited by cognitive decline and I am unable to learn new tasks and take on new responsibilities. 	 NONE of the "Don't Say" column tells the assessor what is happening with you and this information will cause the application to be denied.
 My child is unable to walk without use of equipment. My child is NOT performing at grade level, and requires special accommodations at school including 	My child is disabled

$\overline{igstyle{\Lambda}}$ Do I need a lawyer and how do I find a lawyer:

Technically you do not need a lawyer to apply for SSI. If you or your family is thorough and completes the application and provides the necessary documentation discussed above, you should NOT need a lawyer. If your application is denied and you completed all the steps/recommendations above, you may wish to consult your HD care team for advice and seek attorney if you feel necessary. Many families navigate this process successfully without an attorney, it can be stressful and you may have to appeal an initial denial but does not require attorney involvement unless you want it.

<u>Finding A Lawyer:</u> Social Security is a FEDERAL program; therefore, you can have an attorney licensed in any state represent you.

National Organization of Social Security Claimants' Representatives (NOSSCR)

•https://nosscr.org/referral-service/ These attorney's specialize in representing families through Social Security disability claims (may not assist with initial applications, services may be after a denial). They will charge a fee - generally portion of back pay.

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•You can often do a search at county or state Bar Association websites to find attorney's that are licensed and in good standing.



For specific Evaluation Criteria from SSA please visit:

Adults (Over 18)

Click on Sec 11.00, Neurological Disorders, and scroll down to 11.17 Section or 112.02

https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm

Under 18 (JoHD)

Click on Sec 111.00, Neurological Disorders, and scroll down to 111.17 Section or 112.02

https://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

Information shared in this document is from www.ssa.gov: Social Security Red Book and Social Security Blue Book, List of Impairments, as well as disability tips shared by Allison Bartlett, Esq, Manager of Disability Programs @ HDSA &

FOR MORE INFORMATION VISIT:

HDSA.org Social Security Administration Special Needs Alliance Disability Rights California



Advance Care Planning: An Overview

Lisa Mooney, LCSW

You have a right to make your own medical decisions at all stages of your adult life. Advance Care Planning is a process of discussing, preparing and documenting your wishes and/or preferences. Decisions are based on your personal beliefs and values. The topics listed below can be very difficult to think about and talk about. Advance care planning is an ongoing process of discussion and you don't have to make all your decisions right now, but discussing what you are thinking in regards to the topics below will assist you and your loved ones in caring for you both now and at end of life.

What to think about:

Medical Preferences regarding:

- ✓ pain management
- ✓ artificial nutrition and hydration
- ✓ intubation
- √ resuscitation
- ✓ dialysis
- ✓ antibiotics
- ✓ any treatments you would or would not want

What is IMPORTANT TO YOU at end of

life?

- ✓ Having family/friends visit often
- ✓ Being pain free
- ✓ Dignity
- ✓ Quality of Life
- ✓ Having closure
- ✓ Religious/Spiritual preferences

Where do you wish to be cared for specifically at end of life?

- ✓ Home
- ✓ Community

Who do you trust to make decisions and follow your wishes?

- ✓ Spouse
- √ Children
- ✓ Friend

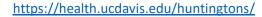
Who to share with:

When selecting person(s) to make your decisions you may want to consider choosing someone who is:

- responsible
- trustworthy to carry out your wishes as expressed
- shares your values and beliefs
- willing to accept responsibility and be available IF decisions need to be made.

- loved ones (trusted family, friends, children, etc.)
- physicians
- social worker
- lawver
- financial advisor







Tips and Reminders:

Speak openly and honestly about your beliefs, values, hopes and fears.

Explore your care options and available resources (Community Care Facilities, Hospice, etc)

You may change your wishes at any time.

Under state law you will be the person making your decisions if you are determined to have capacity and understanding about the decisions you are making. Two physicians and/or the State will determine your capacity as needed.

Ask questions to health care professionals about what to expect regarding your health situation.

Questions to consider:

Intubation (breathing tube):

If I am unable to breathe on my own, *I would or would not* want a machine to permanently breathe for me.

Resuscitation:

If I am am ill with no reasonable hope of recovery, <u>I</u> would or would not want chest compressions (CPR) if my heart should stop.

Antibiotics:

If I am at the end stages of life and I get an infection, <u>I would</u> or would not want IV antibiotics to treat the infection and prolong my life.

Comfort:

If I am at the end stages of life and was having trouble breathing *I would or would not* want oxygen for comfort.

Pain Management:

If I am in the final stages of life and i pain, <u>I would or would not</u> want my physician to provide pain control, using narcotics if necessary.

Nutrition:

If I am unable to sustain my nutritional needs eating by mouth <u>I</u> would or would not want a tube (PEG) placed in my stomach for feeding.

MORE INFORMATION: Advance Care Planning Web Search

National Institute on Aging

QAARP

Coalition for Compassionate Care of California



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1 Choose a medical decision maker, Page 3

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

This person will be your advocate.

They are also called a health care agent, proxy, or surrogate.

Part 2 Make your own health care choices, Page 7

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3 Sign the form, Page 13

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 14, or a notary on Page 15.



This is a legal form that lets you have a voice in your health care.

It will let your family, friends, and medical providers know how you want to be cared for if you cannot speak for yourself.

What should I do with this form?

- Please share this form with your family, friends, and medical providers.
- Please make sure copies of this form are placed in your medical places you get care.

What if I have questions about the form?

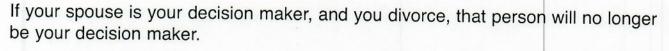
- It is OK to skip any part of this form if you have questions or do not want to answer.
- Ask your doctors, nurses, social workers, family, or friends to help.
- Lawyers can help too. This form does not give legal advice.

What if I want to make health care choices that are not on this form?

On Page 12, you can write down anything else that is important to you.

When should I fill out this form again?

- If you change your mind about your health care choices
- If your health changes
- If your medical decision maker changes



Give the new form to your medical decision maker and medical providers. Destroy old forms.

Share this form and your choices with your family, friends, and medical providers.



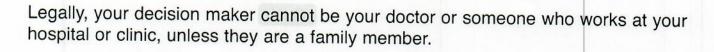
Part 1

Choose your medical decision maker

Your medical decision maker can make health care decisions for you if you are not able to make them yourself.

A good medical decision maker is a family member or friend who:

- is 18 years of age or older
- can talk to you about your wishes
- can be there for you when you need them
- you trust to follow your wishes and do what is best for you
- you trust to know your medical information
- is not afraid to ask doctors questions and speak up about your wishes



What will happen if I do not choose a medical decision maker?

If you are not able to make your own decisions, your doctors will turn to family and friends or a judge to make decisions for you. This person may not know what you want.

If you are not able, your medical decision maker can choose these things for you:

- doctors, nurses, social workers, caregivers
- hospitals, clinics, nursing homes
- medications, tests, or treatments
- who can look at your medical information
- what happens to your body and organs after you die



Here are more decisions your medical decision maker can make:

Start or stop life support or medical treatments, such as:



 CPR or cardiopulmonary resuscitation cardio = heart • pulmonary = lungs • resuscitation = try to bring back This may involve:

- pressing hard on your chest to try to keep your blood pumping
- electrical shocks to try to jump start your heart
- medicines in your veins



Breathing machine or ventilator

The machine pumps air into your lungs and tries to breathe for you. You are not able to talk when you are on the machine.

Dialysis

A machine that tries to clean your blood if your kidneys stop working.



Feeding Tube

A tube used to try to feed you if you cannot swallow. The tube can be placed through your nose down into your throat and stomach. It can also be placed by surgery into your stomach.

- Blood and water transfusions (IV) To put blood and water into your body.
- Surgery
- Medicines



End of life decisions your medical decision maker can make:

- call in a religious or spiritual leader
- decide about autopsy or organ donation
- decide if you die at home or in the hospital
 decide about burial or cremation

By signing this form, you allow your medical decision maker to:

- agree to, refuse, or withdraw any life support or medical treatment if you are not able to speak for yourself
- decide what happens to your body after you die, such as funeral plans and organ donation

If there are decisions you do not want them to make, write them here:

ONLY after	edical decision maker make of ar I am not able to make my of after I sign this form an write why you feel this way.	wn decisions	
	ne of your medical decison to make my medical decis		o make my own:
phone #1	phone #2	relationship	
address	city	state	zip code
#2: If the first perso	on cannot do it, then I want this	person to make my m	edical decisions:
first name	last name		
phone #1	phone #2	relationship	

city

address

zip code

state

Why did you choose your medical decision maker?

If you want, you can write why you chose your #1 and #2 decision makers.

Write down anyone you would NOT want to help make medical decisions for you.

How strictly do you want your medical decision maker to follow your wishes if you are not able to speak for yourself?

Flexibility allows your decision maker to change your prior decisions if doctors think something else is better for you at that time.

Prior decisions may be wishes you wrote down or talked about with your medical decision maker. You can write your wishes in Part 2 of this form.

Put an X next to the one sentence you most agree with.

Total Flexibility: It is OK for my decision maker to change any of my medical decisions if my doctors think it is best for me at that time.
Some Flexibility: It is OK for my decision maker to change some of my decisions if the doctors think it is best. But, these wishes I NEVER want changed:
No Flexibility: I want my decision maker to follow my medical wishes exactly. It is NOT OK to change my decisions, even if the doctors recommend it.

If you want, you can write why you feel this way.

To make your own health care choices, go to Part 2 on Page 7. If you are done, you must sign this form on Page 13.

Please share your wishes with your family, friends, and medical providers.

Part 2

Make your own health care choices

Fill out only the questions you want.

How do you prefer to make medical decisions?

Some people prefer to make their own medical decisions. Some people prefer input from others (family, friends, and medical providers) before they make a decision. And, some people prefer other people make decisions for them.

some pe	eople prefer other people make decisions for them.
Please informat	note: Medical providers cannot make decisions for you. They can only give tion to help with decision making.
How do	you prefer to make medical decisions?
	I prefer to make medical decisions on my own without input from others. I prefer to make medical decisions only after input from others. I prefer to have other people make medical decisions for me.
If you w	ant, you can write why you feel this way, and who you want input from.
What i	matters most in life? Quality of life differs for each person.
	most important in your life? Check as many as you want.
	Your family or friends
	Your pets
	Hobbies, such as gardening, hiking, and cooking Your hobbies
	Working or volunteering
	Caring for yourself and being independent
	Not being a burden on your family
	Religion or spirituality: Your religion
	Something else
	nge your life iov? What are you meet leading to the contract of the contract o

What brings your life joy? What are you most looking forward to in life?

What matters most for your medical care? This differs for each person.

For some people, the main goal is to be kept alive as long as possible even if:

- They have to be kept alive on machines and are suffering
- They are too sick to talk to their family and friends

For other people, the main goal is to focus on quality of life and being comfortable.

These people would prefer a natural death, and not be kept alive on machines

Other people are somewhere in between. What is important to you?

Your goals may differ today in your current health than at the end of life.

TODAY, IN YOUR CURRENT HEALTH

Put an X along this line to show how you feel today, in your current health.

My main goal is to live as long as possible, no matter what.

Equally important

My main goal is to focus on quality of life and being comfortable.

If you want, you can write why you feel this way.

AT THE END OF LIFE

Put an X along this line to show how you would feel if you were so sick that you may die soon.

My main goal is to live as long as possible, no matter what.

Equally important

My main goal is to focus on quality of life and being comfortable.

If you want, you can write why you feel this way.

Quality of life differs for each person at the end of life. What would be most important to you?

AT THE END OF LIFE

Some people are willing to live through a lot for a chance of living longer.

Other people know that certain things would be very hard on their quality of life.

 Those things may make them want to focus on comfort rather than trying to live as long as possible.

as long as possible.
At the end of life, which of these things would be very hard on your quality of life? Check as many as you want.
Being in a coma and not able to wake up or talk to my family Not being able to live without being hooked up to machines Not being able to think for myself, such as severe dementia Not being able to feed, bathe, or take care of myself Not being able to live on my own, such as in a nursing home Having constant, severe pain or discomfort Something else
OR, I am willing to live through all of these things for a chance of living longer.
If you want, you can write why you feel this way.
What experiences have you had with serious illness or with someone close to you who was very sick or dying? • If you want, you can write down what went well or did not go well, and why.
If you were dying, where would you want to be? at home in the hospital either lam not sure What else would be important, such as food, music, pets, or people you want around you?

How do you balance quality of life with medical care?

Sometimes illness and the treatments used to try to help people live longer can cause pain, side effects, and the inability to care for yourself.

Please read this whole page before making a choice.

AT THE END OF LIFE, some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

Life support treatment can be CPR, a breathing machine, feeding tubes, dialysis, or transfusions.



Check the one choice you most agree with.

If you were so sick that you may die soon, what would you prefer?

Try all life support treatments that my doctors think might help. I want to stay on life support treatments even if there is little hope of getting better or living a life I value.
Do a trial of life support treatments that my doctors think might help. But, I DO NOT want to stay on life support treatments if the treatments do not work and there is little hope of getting better or living a life I value.
I do not want life support treatments, and I want to focus on being comfortable. I prefer to have a natural death.

What else should your medical providers and decision maker know about this choice? Or, why did you choose this option?

Your decision maker may be asked about organ donation and autopsy after you die. Please tell us your wishes.

ORGAN DONATION

Some people decide to donate their organs or body parts. What do you prefer? I want to donate my organs or body parts. Which organ or body part do you want to donate? Any organ or body part Only I do not want to donate my organs or body parts. What else should your medical providers and medical decision maker know about donating your organs or body parts? AUTOPSY An autopsy can be done after death to find out why someone died. It is done by surgery. It can take a few days. I want an autopsy.

FUNERAL OR BURIAL WISHES

about my death.

I do not want an autopsy.

I only want an autopsy if there are questions

What should your medical providers and decision maker know about how you want your body to be treated after you die, and your funeral or burial wishes?

- Do you have religious or spiritual wishes?
- Do you have funeral or burial wishes?

art 2: Make your own health care choices	California Advan	ce Health Care Directive
What else should your medical provide maker know about you and your choice	rs and medica	al decision
OPTIONAL: How do you prefer to get medic	cal information	?
Some people may want to know all of their medical	information. Othe	r people may not.
If you had a serious illness, would you want you to tell you how sick you are or how long you ma Yes, I would want to know this information.	y have to live?	edical providers
No, I would not want to know. Please talk v		naker instead.
If you want, you can write why you feel this way.		

* Talk to your medical providers so they know how you want to get information.

Part 3

Sign the form



Before this form can be used, you must:

- sign this form if you are 18 years of age or older
- have two witnesses or a notary sign the form

Sign your name and write the date.

sign your name		today's date	
print your first name	print your last name	date	of birth
address	city	state	zip code

Witnesses or Notary

Before this form can be used, you must have 2 witnesses or a notary sign the form. The job of a notary is to make sure it is you signing the form.

Your witnesses must:

- · be 18 years of age or older
- know you
- agree that it was you that signed this form

Your witnesses cannot:

- be your medical decision maker
- be your health care provider
- work for your health care provider
- work at the place that you live (if you live in a nursing home go to Page 15)

Also, one witness cannot:

- be related to you in any way
- benefit financially (get any money or property) after you die

Witnesses need to sign their names on Page 14.
If you do not have witnesses, a notary must sign on Page 15.



Have your witnesses sign their names and write the date.

By signing, I promise that _ signed this form. (the person named on Page 13)

They were thinking clearly and were not forced to sign it.

I also promise that:

- I know this person or they can prove who they are
- I am 18 years of age or older
- I am not their medical decision maker
- I am not their health care provider
- I do not work for their health care provider
- I do not work where they live

One witness must also promise that:

- I am not related to them by blood, marriage, or adoption
- I will not benefit financially (get any money or property) after they die

Witness #1 sign your name date print your first name print your last name address city state zip code Witness #2 sign your name date print your first name print your last name

city

You are now done with this form.

address

Share this form with your family, friends, and medical providers. Talk with them about your medical wishes. To learn more go to www.prepareforyourcare.org



state

zip code

Notary Public: Take this form to a notary public ONLY if two witnesses have not signed this form. Bring photo ID (driver's license, passport, etc.).

		alidity of that document.
State of California County of		
Date Defore me	Here insert name and title of the officer	, personally
appeared	Here insert name and title of the officer Names(s) of Signer(s)	
the within instrument and acknowled capacity(ies), and that by his/her/the of which the person(s) acted, execut I certify under PENALTY OF PERJUIS true and correct. WITNESS my ha	dged to me that he/she/they executed the sa eir signature(s) on the instrument the person ted the instrument. IRY under the laws of the State of California and and official seal.	me in his/her/their authorized (s), or the entity upon behalf
SignatureSignature of No	otary Public	
Description of Attached Document Title or type of document: Date: Number of pages:	t	
Capacity(ies) Claimed by Signer(s)		
Signer's Name: O Individual O Guardian or conservator O Other		(Notary Seal)
For California Nursin	g Home Residents ONLY	
Give this form to your nursing home	director ONLY if you live in a nursing home. nursing home ombudsman as a witness of a	California law requires
STATEMENT OF THE PATIEN	T ADVOCATE OR OMBUDSMAN	The state of the s
	r the laws of California that I am a patient advoca nat I am serving as a witness as required by Sec	ate or ombudsman as designated tion 4675 of the Probate Code."
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Driving Issues

Lisa Mooney, LCSW

The thought of not being able to drive can be an extremely emotional decision for HD families. It often means loss of independence or freedom to the person with HD which can trigger feelings of depression, isolation and anger. It will likely cause disruption to the family routine as well as emotional stress to both the person with HD and family members. Just having HD does not mean someone is unsafe to drive. The deterioration in concentration, processing information, decision-making, and slower muscle response, eventually will impact the HD person's ability to drive safely. Knowing what to expect and preparing can attempt to make the process as seamless as possible for the HD person and the family.



Start talking about DRIVING early BEFORE there are issues!

How to approach the conversation?

- Remember giving up car keys is best done over a gradual process
- Avoid alienating or calling the person a bad or dangerous driver as they can become defensive.
- Be respectful in remembering driving often means independence and the thought of not driving can trigger some people they are losing a piece of their freedom.

What to Discuss?

Have a plan:

- How will family let the driver know they have concerns?
- Who in the family is best to discuss the issues and safety concerns?
- What community resources and/or medical professionals can assist with safety conversations
- How and who will help the person with transportation once they stop driving

Evaluating Driving Skills

Periodically evaluating the HD persons driving skills may be helpful in identifying issues early and implementing driver safety strategies and/or stopping driving before any incidents/accidents occur.

- Traffic tickets, traffic stops/warnings or had any accidents, near accidents, fender benders, in the last 2 years
- Other drivers honk or pass frequently
- Forget to buckle up, turn on headlights, adjust mirrors, etc.
- Reaction to sudden changes in traffic patterns, sirens/flashing lights
- Trouble seeing other vehicles, bicyclists or pedestrians
- Difficulties merging on/off freeways
- Troubles working the pedals or moving from accelerator to
- Use of mirrors and turning their head to check blind spots
- Miss/ignore stop signs or traffic lights
- Change, weave or drift into other lanes without signaling

Fitness to Drive tool:

http://fitnesstodrive.phhp.ufl.edu/us/

Developed by the University of Florida as a tool to be used by family members/care partners to assess driving safety for their loved one.

- Caregiver completes
- Will ask for demographic information
- Watch videos demonstrating safe driving techniques.
- After videos, answer 54 multiple-choice questions about the driving ability of the person being assessed. After completion, the program provides a scorecard about the person's driving skills with recommendations.
- Takes about 20—30 minutes to complete.



https://health.ucdavis.edu/huntingtons/

Strategies to increase DRIVING SAFETY

Avoid/eliminate distractions

- Turn off radio
- Limit emotional or deep conversations in car
- Put cell phone in back seat

<u>Drive during low traffic</u> times

Periodic behind the wheel driving evaluation of skills and safety

 Some physical therapy/occupational therapy facilities have driving



Slowly reduce how far or often the person drives

staying around town and on familiar roads

Avoid Freeways



Carry HD Wallet card OR window decal

These can help communication to first responders/police about HD symptoms.

Drive during day light hours



Strategies for Resistance to stopping driving

Neutral Person

Seek an objective person to discuss driving concerns

 Doctor, nurse, social worker, church members, neighbors, friends, etc.

Official Driving Evaluations

 Schedule assessment with DMV and let them take the license away as needed.

Report any unsafe driving

Anybody can report safety issues and ask to remain anonymous too.

- ✓ Department of Motor Vehicles
- ✓ Police
- ✓ HD Care Team

Severe or unsafe situations

family may need to prevent the HD person from driving by:

- ✓ hide the car keys or
- ✓ disable the car (i.e. remove battery, "lose keys")
- ✓ call police if they drive

More Resources

AAA Foundation for Traffic Safety California Department of Motor Vehicles



Transportation Resources

Lisa Kjer-Mooney, LCSW

Transportation resources vary widely between cities and counties. You may also find additional transportation resources in your county/city by doing an internet search. Look in you county transportation resources for the following options:



County/City

Public Transportation

To find your transit agency use this link: https://www.apta.com/research-technical-resources/public-transportation-links/california/

OR

internet search for public tranportation agency in your county/city.

nsurance

Medi-Cal

https://www.dhcs.ca.gov/services/medi-cal/Pages/Transportation.aspx

OR

calli your Medi-Cal Insurance Health Plan





I have Huntington's Disease (HD)
I MAY appear to be intoxicated due
to my symptoms.

I may have any or all of these symptoms:

Movements I cannot control, impaired gait, delayed responses, slurred speech, trouble following directions, increased agitation and anxiety.



If I need assistance, please contact:

Name:

Phone Number:

Address:

Individual with Huntington's Disease On Board!

In case of an emergency, please be aware that the individual:

- May not be able to speak or articulate pain or injury
- May not be aware of the situation
- May be resistant to any help from first responders
- May appear to be intoxicated or on narcotics due to symptoms of Huntington's disease



Interacting with Community Responders:

Law Enforcement, Emergency Medical Technicians, Firefighters, etc.

Lisa Kjer-Mooney, LCSW

HD families are essential in the education of community professionals (such a police officers, judges, lawyers, and emergency responders, etc) about HD and the impact HD has on a person's physical, cognitive and behavioral abilities and/or limitations. Providing information about HD during interactions with community professionals is an important way to raise awareness and avoid injustices for HD persons.



Ways to Educate and Advocate with Community Responders

Contact local police, fire stations, neighbors and businesses to provide brief information about your loved one with HD.

If you have experienced negative interactions with community responders you may ask your HD care team to write a letter on your behalf to relay important information about HD and his/her current symptoms, limitations and medications.

Share any information that is helpful to communicate and assist as well as avoid misunderstandings or improper detainment of a person. For example:

- HD persons need extra time to process questions and respond;
- make eye contact to ensure they can focus;
- when giving tasks/commends state one at a time for better comprehension by HD person, and provide information about any balance and chorea issues, etc.

AFTER initial emergency situations have resolved, be proactive and problem solve with community responders on how to prevent future incidents. For example:

- have medical id bracelet/information,
- list of emergency contact persons on file or in persons wallet that can provide information if an incident occurs



Resources to Share

Law Enforcement Tool Kits

HDSA and Help4HD offer information that has already been gathered and can be printed and given to community responders.

HD written resources

Visit HDSA, Help4HD or UC Davis HD Center of Excellence can be downloaded for free and provided to community responders. "I Have Huntington's Disease"
wallet card or
identification/medical alert
bracelet recommended for all HD
persons as it can be useful in
providing quick information about
HD, as well as who to contact in
emergency situations.

HDSA.org

Help4HD.org

UC Davis HDSA Center of Excellence



How can I help? should I call a lawyer? rong? What should I do? ?What is HD? do? What's wrong? How can I help? at's wrong? What is HD? When should I call a lawyer? help? What should I do? does_HD look like? What's wrong? /hat can be do should I call a lawyer? What does HD look like? wrong? What do I need to know about HD? p? What does HD look like? n should I call a lawyer? hat should I do? How can I help? What do I need to know about HD? nat can be done? How can I help? What is H

Caregiver Guide



Caregiver Guide

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Disclaimer

Statements and opinions in this guide are not necessarily those of the Huntington's Disease Society of America, nor does HDSA promote, endorse, or recommend any treatment or therapy mentioned herein. The reader should consult a physician or other appropriate healthcare professional concerning any advice, treatment or therapy set forth in this publication.

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Preface

It's a sad fact, but if you are a caregiver for a loved one with Huntington's disease, you have probably either [a] already experienced situations where law enforcement has been involved in your lives or [b] probably will be sometime in your future!

When I cared for my daughter Kelly, who had Juvenile HD, we went through some very painful years of her running away, taking drugs, threatening suicide, 'borrowing' my car without permission, etc. all before the ripe old age of 15! Around the age of 18, I thought the hardest part was over once she started showing more physical symptoms of HD, and wasn't quite as mobile as she would have liked. Wishful thinking, because then we fought not only the discrimination that comes from people ignorant about HD, but sometimes out and out harassment from local law enforcement personnel.

I can't remember all of the times Kelly, whose favorite thing to do was to hang out at the beach, was hauled off to the police station under suspicion of being drunk or being on drugs. Fortunately, knowing people couldn't understand her speech, Kelly carried her HDSA "I Have HD" card with her everywhere that instructed people to call me in case of an emergency. Once I explained over the phone what HD was, the police typically said for me to come in and pick her up.

When I went, I was always armed with brochures on Huntington's disease to hand out, but the next time a different officer saw Kelly talking to strangers and slurring her words... off to jail she'd go again!

Those years were beyond frustrating for us, which is why I'm elated that this manual for caregivers provides you with the guidelines to arm yourself by utilizing some of the suggestions contained here that may avoid heartbreak for you and your family in the future.

By Jean Miller, HDSA Patient Advocate Clearwater, FL

Introduction

There may be times during the continuum of Huntington's disease (HD) when confrontations arise between you and your loved one over unsafe or socially unacceptable behavior. During these times, law enforcement personnel may become involved.

Law Enforcement (LE), in the context of this document, includes any official personnel, local or state, who have the official capacity to respond to emergency situations: Police, State Patrol, Deputized personnel, Paramedics, EMTs, Emergency Medical responders, as well as security personnel at department stores, shopping malls, hospitals, etc.

This guide was developed to provide concrete suggestions and useful advice to you for these times of conflict. Being prepared for potential confrontations can ensure the best outcome for all concerned.

Problems may arise when law enforcement personnel, responding to a call involving your loved one, are unfamiliar with Huntington's disease. They may misinterpret the aggressive behavior, inability to obey directives and combative response to restraint by the person with HD as willful defiance. An unsteady gait, balance problems and slurred speech can easily be misread as intoxication. It may fall

on the caregivers and family members to be HD educators and advocates, as well as to effectively communicate on behalf of their loved one.

The issues discussed in this guide are not meant to imply that every person with HD will demonstrate socially unacceptable behaviors or that the behaviors will escalate to the level of legal action. The goal is to help caregivers and family members be prepared to respond constructively during an incident.

It is recommended that you read this entire guide before a serious situation or crisis takes place. The suggestions on what you can do, as well as what to avoid, can guide you in making good choices in challenging situations. Taking the time to think about potential confrontations before they occur may even help you to defuse a situation before it is necessary to call the authorities.

This guide is one part of HDSA's Law Enforcement Toolkit. If you would like more information please contact the HDSA national office at 800-345-HDSA.

GENERAL GUIDELINES FOR MANAGING AN ENCOUNTER BETWEEN A PERSON WITH HD AND LAW ENFORCEMENT OR OTHER EMERGENCY SERVICES PERSONNEL:

Misunderstanding and conflicts may arise when emergency services personnel are not familiar with Huntington's disease or lack knowledge of the complexity and severity of its symptoms.

Creating a Plan/Before Law Enforcement Becomes Involved:

- Take the first step and reach out to your local Law Enforcement.
 Using the Law Enforcement Toolkit, provide information on HD and what HD means for your loved one.
 Introduce your loved one to the local Law Enforcement.
- Encourage your loved one to carry an "I Have HD" card or another identifier of HD. Keep an updated HD Profile Card in an easily accessible place in case of an emergency. A Profile can also be provided to the local LE so they can become familiar with your loved one and their symptoms. An HD Profile Card is included as part of the Law Enforcement Toolkit.

- Think about what you would do in case of emergency. Fill out a Crisis Template and be sure it is kept up to date. A Crisis Template is included as part of the Law Enforcement Toolkit. Talk to your HDSA social worker or other trusted professionals to discuss local resources available to you.
- Research your loved one's legal rights.
 Talk to an HD-knowledgeable attorney or an attorney that is familiar with the Americans with Disabilities Act.
 Creating a relationship with a lawyer early on can help save time and energy in case of an emergency. Please see the "Legal Resources" section in the back of this guide for more information on finding an attorney.

- The responsibility of LE is to protect the safety and welfare of the public, including your loved one. During your first conflict with LE, talk to the police to discuss how the situation can be prevented in the future.
- Dealing with LE can sometimes be a frustrating and confusing experience.
 Using a calm tone and attitude during the incident can help the situation go smoothly and help keep your loved one calm should they start getting agitated.
- Keep your hands visible at all times.
- Do not attempt to convince the LE officer to leave the situation or ignore it.
 Once the encounter has begun, LE may be required to take some action and/or create some sort of report.

SITUATIONS THAT MAY CAUSE SOCIAL CONFLICTS OR ENCOUNTERS

There are many reasons why a person with HD might have an encounter with emergency services personnel. Some incidents will occur because of misperceptions of HD symptoms, even though the person with HD is entirely innocent. Others will happen because of socially unacceptable or dangerous behaviors caused by symptoms of the disease.

Misperception of drug or alcohol intoxication

Symptoms of HD, such as slurred speech and unsteady gait, can create the impression of intoxication. The goal is to prevent the misunderstanding from escalating into a conflict.

Creating a Plan/Before Law Enforcement Become Involved:

 Learn about public intoxication laws in your state to help you speak with emergency service officials and LE personnel.

- A Breathalyzer test can help clear up the misperception that your loved one is intoxicated. In some areas, refusal to take a Breathalyzer test can lead to an arrest for public intoxication.
- Do not automatically assume that your loved one is sober. Your loved one may be intoxicated without your knowledge.

Shoplifting

Changes to the brain caused by the disease will make a person with HD impulsive and less able to resist the temptation to take something they want without paying for it. The person with HD may forget or minimize the consequences of stealing from a store.

Creating a Plan/Before Law Enforcement Become Involved:

- If you see your loved one shoplifting, try to stop the situation in a calm manner. Say something like: "If you want this [item], we can take it to the checkout."
- Try to distract your loved one and replace the item before leaving the store.
- If the situation allows, find a quiet place to have a calm discussion. Explain the potential consequences of the actions to your loved one.

When Dealing with Law Enforcement:

- If your loved one is stopped for shoplifting, try to explain the biological basis for the behavior to the Law Enforcement/store staff. Offer to pay for the item or return it, if possible.
- Try not to become belligerent or deny the behavior to the store staff or LE. Explain that the behavior is a symptom of a disease and ask for their compassion.
- Do not participate in or cover up for illegal behavior.
 Shoplifting is a crime.

Inappropriate Sexual Behavior

Social disinhibition is a symptom of HD, as is the reduced ability to delay gratification. This can lead to behavior that is embarrassing and disturbing to caregivers and family members. The goal is to manage the behavior in a safe way.

Creating a Plan/Before Law Enforcement Become Involved:

- A person with HD who exhibits sexually inappropriate behavior should never be left alone with minors.
- If the person with HD removes clothing, gently discourage the behavior.

- If a person with HD is masturbating in a room with others, tell them they need to do that privately. If they attempt to continue, bring them to a bathroom or their bedroom.
- If your loved one touches others inappropriately, remind them that the behavior is inappropriate and that they can be arrested.
- Keep a calm, matter-of-fact and orderly demeanor when discussing inappropriate sexual behavior. If you become loud, anxious, impatient or upset, so will the person with HD
- Watch for romantic or sexual obsessions. Make it clear that stalking is inappropriate and illegal. Speak to your loved one's physician if obsessions become worrisome.
- Understand that your loved one may fixate on a sexual idea or behavior and have difficulty controlling these thoughts.
- Do not ignore inappropriate sexual behavior. It may escalate to sexual abuse or assault if not addressed.
- Seek counseling for the person with HD, or for yourself, if changes in sexual behavior affect your intimate relationship.

- Be aware that the lack of impulse control associated with HD can lead to promiscuity; this can also make the person with HD an easier target for abuse.
- Talk to your children and develop a response or plan to deal with this behavior.
- Let your children know that you are there for them and available to talk about anything.

- If your loved one continues to exhibit inappropriate sexual behavior in a dangerous situation, call your local LE for help in dealing with the problem.
- A person with HD, exhibiting inappropriate behaviors, may be labeled as a sex offender.

Sexual Abuse

Changes to the brain and reduced impulse control caused by HD can result in aggressive or dangerous sexual behavior that must be controlled.

Creating a Plan/Before Law Enforcement Become Involved:

 Medication may help the person with HD control their behavior. Talk to your loved one's physician about disturbing behavior before it escalates to assault or abuse.

When Dealing with Law Enforcement:

- Recognize that no one is allowed to force themselves sexually on another person. Spouses and children are protected under the law.
- Call law enforcement as soon as possible if abuse or the threat of abuse occurs. Protect yourself and your children by leaving, if possible.
- Allow the law enforcement officers to make an arrest. Pressing charges will help prevent the abuse from happening again.
- Do not keep the abusive sexual behavior a secret. Allowing a child to be abused is a crime.

- Get counseling for all involved parties.
- There is no shame in being a victim of abuse. Keep your focus on ending the abuse.
- Do not leave yourself or your family in a dangerous situation. Call law enforcement for help and talk to your local HDSA social worker or a trusted professional.
- For help in responding to sexual abuse, please contact RAINN's national sexual abuse hotline at 1.800.656.HOPE or via the web at www.rainn.org or the National Domestic Violence Hotline at 1.800.799.SAFE or via the web at www.thehotline.org. These numbers and websites are included on the Crisis Template, which is available as part of the HDSA Law Enforcement Toolkit.
- Have a plan in place to go to a safe place if needed until the situation deescalates.

Aggression

Explosive behavior and aggression are common symptoms of HD that may be manageable. It may be possible to identify some of the triggers and frustrations that lead to angry outbursts in order to defuse a confrontation.

Creating a Plan/Before Law Enforcement Become Involved:

- Don't wait for a crisis to think about what you would do in case of emergency. Fill out a Crisis Template and be sure it is kept up to date.
- Attempt to identify the source of the aggression and the root cause of the anger. This is usually why the aggression is taking place. Keep in mind that the root cause of the anger may not be based in reality.
- When talking with a person with HD
 who is getting aggressive, slow your
 speech, quiet your voice and keep
 your posture as relaxed as possible.
 Do not attempt to touch your loved
 one, as that might be interpreted as an
 aggressive act.
- Inform the person with HD that he or she is losing control and is scaring you.
- Use a firm and calm voice to tell the person with HD to stop yelling, hitting or kicking.

- Never put yourself in physical danger.
 Do not hesitate to leave the house or lock yourself in a secure room and phone for help if the situation escalates.
- Be aware of your physical surroundings and of cues. Keep an arm's length away and try to keep a clear pathway to the door.
- Do not get into a fighting stance or threaten the person with HD. Act confidently but not combatively to defuse the situation.
- Have an escape plan should the situation get dangerous. Talk to an HDSA social worker or a trusted professional about creating a safety plan and escape routes.
- Keep in mind that aggression may be medically manageable. If your loved one has symptoms of aggression, talk to their doctors about possible medication.
- When the crisis has passed, do not lie to the person about their aggression.
 They are usually aware of what they are doing and are acting out from fear or impulsivity.

- If you are in danger, get yourself to a safe house and contact your local law enforcement immediately. LE can help protect you and your loved ones and diffuse the situation
- For help in dealing with domestic violence, you can contact Safe Horizon at 1.800.621.HOPE (4673) or via the web at www.safehorizon.org or the National Domestic Violence Hotline at 1.800.799.SAFE (7233) or via the web at www.thehotline.org.

Driving

The complex symptoms of HD will interfere with the ability to drive and ultimately it will be necessary for the person with HD to give up this privilege.

Creating a Plan/Before Law Enforcement Become Involved:

- Talk truthfully with your loved one about specific unsafe behaviors you have observed when they are driving. Explain that the behaviors are putting many people in danger.
- Try to understand that driving represents adult independence to many people. The person with HD will be emotional about losing the ability to drive.

- Drive with your loved one regularly to continue to assess their driving competency.
- Take preventative steps when you notice a decline in the driving skills of the person with HD. Offer to drive or arrange for rides.
- If you become concerned about your loved one's driving, contact the Department or Bureau of Motor Vehicles in your state to obtain information about how to have someone retested and/or how driving privileges can be revoked. Your HDSA social worker might also know this information. You may also be able to schedule a driving assessment at your local driving school for a fee or through an HD-knowledgeable Occupational Therapist.
- Advise your loved one to carry medical or disability documentation in the car that identifies them as a person with HD.
- Ask a physician or social worker to help you convince your loved one to stop driving when the time comes and to set benchmarks for that decision.
- If you believe your loved one is no longer able to drive safely, refuse to get into the car with him or her.

- Hiding the car keys rarely works.
 The person with HD may become aggressive or simply call alocksmith.
 Remove the car from the premises, if possible.
- Think about installing an ignition lock or another anti-theft device that makes it difficult for the person with HD to drive.

- If the person with HD insists on driving, explain that the police will be involved if the person with HD drives in an unsafe manner. Be responsible and follow through with the consequences you have described.
- If your loved one gets stopped by law enforcement officers when you are in the car, do not let the person with HD drive away. Turn off the ignition, if need be.
- Do not attempt to mislead law enforcement officers. Tell them that your loved one has a medical condition that affects driving.

Disappearance/Missing Person:

Reduced impulse control and unquestioning trust in others may lead a person with HD to leave home and forget or refuse to tell caregivers and family where they are.

Creating a Plan/Before Law Enforcement Become Involved:

- If possible, give your loved one a cell phone, and ensure that it has some sort of tracking software. If the person were to wander off, you can track them on the internet or on a smart phone. Consider not telling your loved one with HD that you have this tracking software, because if they know it and get angry, they could disable this function themselves. Ask your cell phone provider for more information.
- If your loved one has a habit of wandering off and getting lost, utilize the HD Profile provided by HDSA to inform your local LE about your loved one. This will help search for your loved one should they go missing.
- Make sure you have lots of photos of your loved one along with a list of places they might wander off to.

- If you cannot locate your loved one in a reasonable length of time, call law enforcement for help.
- When you call law enforcement, use the words 'vulnerable adult' or 'at-risk' to describe your loved one.
- Have an up-to-date photo of your loved one you can show to the law enforcement officers.
- Do not feel guilty that you are asking for assistance in locating your loved one. It is not necessary or even helpful for you to do this alone.

IF YOUR LOVED ONE IS ARRESTED OR DETAINED:

When circumstances lead to the arrest of a person with HD, the caregiver has an important role to play as educator and advocate.

- At the time of the arrest:
 - Include a request to talk to medical staff or make sure they are informed the person has Huntington's disease.
 Leave information about HD and a copy of your loved one's HD profile, if you have it. Request that materials be given to the medical staff. Free materials to hand out can be requested from the HDSA National office by calling 888-HDSA-506.
 - Write down names, date, and time and take notes on any discussion with the arresting officer, or law enforcement staff. Ask to be kept informed.
 - Advise your loved one not to answer any questions and to ask for a lawyer.
 - Ask the arresting officers for the name and location of where your loved one is being taken.
- As soon as you can, go to the police station.

- Do not hesitate to ask a friend or relative to go with you to the police station.
 Dealing with an arrest is a difficult situation. Having someone with you can provide emotional strength.
- When you go to the station, bring a copy of your loved one's HD Profile
- If you can, wait for your loved one to be processed and for bail to be set. In some cases the court may release the person "on his own recognizance" or on a "promise to appear in court" and no bail will be required.
- At the police station be sure that your loved one requests that a lawyer be called.
- Ask questions if you do not understand what is happening.
- After a lawyer arrives, heed the lawyer's advice when answering police questions.
- Reassure yourself that you have done what you had to do to.
- Do not interfere with the arresting officers or other law enforcement officers. Getting yourself arrested for interfering will not help your loved one.

PEOPLE AND ORGANIZATIONS THAT CAN HELP YOU AFTER THE ARREST:

Agencies and Organizations:

While HDSA does not have the capacity to provide individual legal assistance, an HDSA social worker can offer education and support to your loved one's attorney. The social worker can also supply a list of resources for information and services that you may find helpful.

- Contact the HDSA National Helpline for publications and information on resources.
- Talk to an HDSA social worker and other health care and social service professionals in your area about programs to help your loved one.
- Be aware that there are agencies available to protect your loved one's rights as a person with a disability.
- Meet with a social worker or mental health care professional to try to identify the underlying causes of repeated encounters with law enforcement.

- You do not have to face this by yourself. Seek help before you are overwhelmed. A support group or mental health professional can help you and your family cope with the stress of your loved one's arrest. You can find a support group at www.hdsa.org.
- Do not let your loved one go to court without a defense attorney. Everyone has the right to an attorney, even if they cannot pay.

Attorney

The lawyer who will represent the person with HD is the liaison between your loved one, the prosecutor and the police. The more they understand about HD, the better they will be able to help bring the situation to a good resolution.

- Educate your loved one's attorney about HD with HDSA publications:
 - Fast Facts about HD
 - Huntington's Disease:A Family Guide
- Provide the attorney with a copy of your loved one's HD Profile.
- Give all the assistance you can to the attorney. This is the person who will defend your loved one in court. The defense attorney has direct contact with your loved one, and access to the prosecutor. If the defense attorney knows about Huntington's disease, he or she can be an advocate. Sometimes jail may be avoided if a treatment plan has been implemented or can be proposed to the court by the attorney.

KEY POINTS

Be Proactive

There are some steps you and your family can take to help make a crisis situation go as smoothly as possible. If you would like to explore more ways to prepare yourself and your loved one for a conflict, please contact your local HDSA social worker or the HDSA National Helpline at 888-HDSA-506.

- Use technology, such as tracking software, to assist in locating your loved one if they are easily confused or prone to wander. Consider having a local cell phone programmed with contact numbers for you and other family members in case of emergencies. Talk with your telephone provider for more information on programs and options.
- If a family attorney is available, provide information regarding HD and how this condition may affect your loved one physically and behaviorally. In case of a legal problem or question, they are aware of your loved one's needs and can be an advocate as needed.

- Discuss advanced directives with your family as early as possible. Go to www.caringinfo.org to download the advanced directive form for your state. Advanced directives vary by state, but in a crisis situation, can help you and your loved one get the help they deserve.
- Don't forget to constantly update the information for your loved one in case of an emergency. Medications, contact information, etc. may be needed in case of an emergency and time may be saved if you know where it is and the information is correct.

Online Legal Resources

There are national organizations whose websites can help you find local resources to aid you in defending your loved one, including:

Find Law: www.findlaw.com

Offers a list of lawyers in your area.

Law Help: www.lawhelp.org

Find local agencies to handle your complaints. Does not provide direct legal help.

Legal Services Corporation: www.lsc.gov

Has a state by state listing of legal aid societies and other providers of low cost or no cost legal assistance.

National Disability Rights Network: www.napas.org

Provides state-by-state listings of agencies that provide information and advocacy. Look for the agencies working under the Protection and Advocacy for Individual Rights (PAIR) program, as they may offer assistance for the disabled who are incarcerated.

CONCLUSION

One of the best things you can do for you and your family to help avoid problems before they occur is to use this guide to help you create your own plan that contains personal information about your loved one with HD. Then, request a meeting with your local law enforcement so that you can offer that plan and educate them about your loved one.

Jean E. Miller

NOTES	NOTES

HELP FOR TODAY. HOPE FOR TOMORROW.

HDSA Mission

To improve the lives of people with Huntington's disease and their families.

Huntington's Disease Society of America National Office

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I Have Huntington's disease



ADDR	ESS / PHONE
l am	Currently Taking (PLEASE LIST MEDICATION & DOSAGE):
In Ca	se of an Emergency, Please Contact:
NAME	1 / PHONE NUMBER 1
NAME	2 / PHONE NUMBER 2

Profile Card

NAME



Huntington's disease is a genetic, neurodegenerative disorder. Symptoms may include:

- Staggering gait
- Jerking or abrupt movements
- Slurred speech
- Slow response to questions
- Disorientation

- Irritability
- Combativeness
- Impulsive behavior
- Sexually inappropriate behavior
- Explosive outbursts or temper

Primary Care Physician:

NAME
PHONE
Special Instructions [ie: Eating and/or Swallowing difficulties, Seizure prone
(keep calm), Do not use restraints, Becomes violent, Hearing impaired, Eyeglasses, etc.]
HISTORY OF SUICIDE ATTEMPTS: YES NO
Additional Comments:





My Crisis Template

FOR (NAME)
My Loved One's
ATTORNEY
DOCTOR
HEALTH INSURANCE INFO:
IN CASE I HAVE TO LEAVE HOME, I WILL GO TO:
ADDITIONAL INFORMATION/COMMENTS:
Local Resource Information
LOCAL CRISIS HOTLINE
LOCAL DOMESTIC VIOLENCE HOTLINE
HDSA SOCIAL WORKER
POLICE
CHICIDE HOTHING

How can I help? should I call a lawyer? rong? What should I do? ?What is HD? do? What's wrong? **How can I help?** at's wrong? What is HD? When should I call a lawyer? help? What should I do? does HD look like? What's wrong? What can be done? should I call a lawyer? What What does HD look like? s wrong? What do I need to know about HD? p? What does HD look like? n should I call a lawyer? hat should I do? How can I help? What do I need to know about HD? nat can be done? How can I help? What is HI

My Crisis Template



National Resources

Huntington's disease

Huntington's Disease Society of America (HDSA)

HDSA provides information, resources and downloadable publications. Call HDSA to locate an HD social worker in your area.

www.hdsa.org 888-HDSA-506

Legal Resource Websites

Legal Services Corporation

The Legal Services Corporation has a state by state listing of legal aid societies and other providers of low cost or no cost legal assistance.

www.lsc.gov

Find Law

Find Law has a searchable database of legal information, as well as a listing of lawyers.

www.findlaw.com

Law Help

Law Help has a local listing of agencies that provide free legal aid programs and answer questions about legal rights.

www.lawhelp.org

Crisis Hotlines

Safe Horizon

Safe Horizon, the largest victim services agency in the U.S., provides support and advocacy for victims of crime and abuse.

www.safehorizon.org

Domestic Violence Hotline:

800-621-HOPE (4673)

Safe Horizon's Crime Victims Hotline:

866-689-HELP (4357)

Rape Abuse and Incest National Network (RAINN)

The Rape, Abuse & Incest National Network is the nation's largest anti-sexual assault organization. RAINN has a telephone and an online hotline and provides referrals to local resources.

www.rainn.org 800-621-HOPE (4673)

National Domestic Violence Hotline

The National Domestic Violence Hotline is a 24-hour hotline providing support through advocacy, safety planning and local resources

www.thehotline.org 800-799-SAFE (7233)

Suicide Prevention Hotline

www.suicidepreventionlifeline.org 800-273-TALK (8255)



I HAVE HUNTINGTON'S DISEASE

If I appear to behave strangely it is because I have HD. I may slur my words, appear to be distracted or may have trouble walking. I know that I am doing these things. I am aware of what is going on. Please be patient. If I need help, please contact the person listed on the other side of this card. Thank you for your understanding and caring.



Stop! Observe! Assess!

Before you detain a person you suspect is under the influence, please consider that he/ she might have Huntington's Disease or another type of neurological disorder which may present the appearance of intoxication, defiance or refusal to comply.

What is HD?

- Fatal brain disorder
- Cognitive impairment
- Movement disorder
- Emotional disturbances
- Inherited/not contagious

Huntington's Disease (HD) results from genetically programmed degeneration of brain cells, called neurons. This degeneration causes uncontrolled movements, loss of intellectual faculties, and emotional disturbance. Each child of an HD parent has a 50/50 chance of inheriting the HD gene. Some early symptoms of HD are mood swings, depression, irritability or trouble driving, learning new things, remembering a fact, or making a decision. As the disease progresses, concentration on intellectual tasks becomes increasingly difficult.

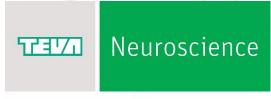
Reference from National Institute of Neurological Disorders and Stroke: http://www.ninds.nih.gov/disorders/huntington/

For more information: www.Help4HD.org

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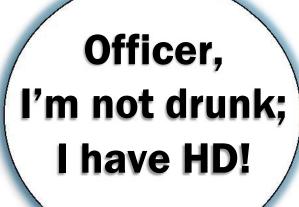
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Huntington's Disease Awareness for Law Enforcement





Scan me!



Sheriff's Deputy Michael Hinshaw, diagnosed in 2007 with Huntington's Disease

What do you see?

- Look for Medic Alert bracelet/necklace
- Stumbling gait
- Loud or agitated
- Chorea (uncontrolled dance-like movements)
- Impaired communication skills

You are on patrol and you observe a person who can't keep his/her balance, or someone calls 911 to report a person who is walking with an odd stumbling gait and appears to be



Image by Diana Kastelic

drunk. His/her movements cannot be stopped even if ordered! Chorea is not kicking or hitting; it is uncontrolled movements.

Maybe he/she created a disturbance in a restaurant. The person is getting loud or agitated; the staff doesn't know how to handle him/her and calls 911.

You hear that his/her speech is slurred and his/her movements are jerky, and he/she seems to have a fixed stare. You conclude, correctly, that this person is impaired.

Is it HD?

- Delayed response
- Loss of memory
- Poor judgment
- Symptoms increased by stress
- Lack of awareness

You begin to ask questions, but he/she does't reply. You instruct him/her to do something, but he/she does't respond. It seems like he/she is resisting or defying your instructions. Complicating resolution, symptoms get worse when the person with HD is under stress. People with HD seem to get frozen at times.

He/she may be able to tell you that he/she have this disorder or he/she may not. An ER or psychiatric receiving facility may be advisable if he/she appears to have psychosis or delusions.

Behaviors!

- Psychosis
- Perseveration (repetitive words/ thoughts/actions)
- Hallucinations
- Rages
- Anosognosia (lack of awareness)

People with HD are protected by the ADA

If you conclude that this behavior is not from intoxication, you may be able to send the person on his/her way or ask if you can call his/her caregiver or family member to come pick him/her up. If you cannot reach the family, a hospital ER or a psychiatric receiving facility is an option.

If the person has violated the law and must be arrested, tell the intake officers that you know or suspect the person has a neurological disorder. The caregivers or family members may need to bring medication to the jail for their loved one. Interruptions in the medication schedule can make behaviors more difficult to manage.

Is he/she homeless?

Some people with HD are homeless. With the stresses of their illness they lose their ability to work. Unless the person has an advocate to help navigate the social services system, he/she may not be able to successfully complete this process. Try to determine if the person has a home to go to; try to call the caregiver or family member. If unreachable, please help the person access the appropriate resources for homeless people in your city or town.

Thank you for protecting the safety, civil rights, dignity and privileges of people with Huntington's Disease.

What to Do if a Person Has HD

Stress can exacerbate symptoms—don't strap them to a backboard; you may need to sedate to get them on a gurney.

Bring a family member along if possible.

Recognize choking and aspiration potential—put patient on at least a 45-degree angle, and do not tie the hands down. You may need to sedate the patient for safety.

Be careful not to misinterpret symptoms; take a helpful, supportive role.

Contact social worker, case manager within hospital to find resources to help the patient.

Check for advance directive, Physician's Order for Life Sustaining Treatment, DNR.

Check for resources attached to the 911 system.

Ask 911 dispatcher to get all possible background information from the family. Ask them to be specific about what's going on and what resources are needed to intervene.

HD/JHD Database—is loved one registered? If so, mention it.

Can request a psychiatric emergency response team (PERT) or a PERT-trained officer.

Request a crisis intervention team if necessary.

Be aware that patients with HD/JHD are covered under the ADA (Americans With Disabilities Act).

Thank you for taking the time to learn more about Huntington's disease.

Help 4 HD
International Inc. is a
501(c)(3) public charity
serving the
Huntington's and
Juvenile Huntington's
disease community.

Thank You To Our Sponsors



Help 4 HD International Inc.

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International's
Informational
Guide for EMTs
and Firefighters
About
Huntington's
Disease



Help 4 HD International Inc. Educating the World About Huntington's Disease

Help 4 HD International Inc.

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What Is Huntington's Disease?

Huntington's disease (HD) is a fatal brain disease resulting from genetically programmed degeneration of neurons in certain areas of the brain. This degeneration causes uncontrolled movements, loss of intellectual and physical faculties, and emotional and behavioral disturbances, including psychosis.

HD is a familial disease, passed from parent to child through a mutation in the normal gene on Chromosome 4. Each child of an HD parent has a 50/50 chance of inheriting the HD gene. If a child does not inherit the HD gene, he or she will not develop the disease and cannot pass it to subsequent generations unless he/she is in the "gray area."

A person who inherits the HD gene will sooner or later develop the disease. Whether one child inherits the gene has no bearing on whether others will or will not inherit the gene.

It is an "equal opportunity" disease, affecting both males and females, all ages, and all ethnic groups. When found in children and adolescents, it is referred to as Juvenile Huntington's disease (JHD).

Some Symptoms of Huntington's Disease (HD)

- DEPRESSION
- ANXIETY
- CHOREA (Involuntary movement)
- TREMORS
- DYSTONIA (Muscle contractions)
- HALLUCINATIONS (Auditory and/or visual)
- PARANOIA
- PSYCHOSIS
- OBSESSIVE COMPULSIVE BEHAVIORS
- APATHY
- SUICIDAL THOUGHTS AND ACTIONS
- DEMENTIA
- DELAYED PROCESSING OF INFORMATION
- IMPAIRED MEMORY

What Do First Responders Need to Know?

People with HD often appear to be drunk or under the influence of drugs, even though they are completely sober.

Someone with HD may or may not be able to tell you that he/she has this disorder.

Symptoms get worse when the person with HD is under stress. The person may not be able to reply to questions or respond to instructions. The person may seem to be kicking or hitting, but is not; that is the chorea, over which the person with HD has no control.

One of the biggest challenges with HD and JHD can be behavioral symptoms. Agitation, aggression, apathy, obsessive compulsive behaviors, and perseveration can cause lots of angst in HD families. Sometimes, these behaviors lead to domestic violence, and family members may call 911 in an effort to obtain help.

What Do First Responders Need to Know? (Continued)

Look for:

- A Medic Alert bracelet/necklace
- A stumbling gait
- · Loud, aggressive, or agitated behavior
- Chorea (uncontrolled dance-like movements that cause parts of the body to twist or writhe) or dystonia (muscle contractions)
- Impaired communication skills, including delayed response time and slurred speech
- A fixed stare or jerky eye movements
- A flat affect (blank, unemotional stare)

Things to Think About

An HD patient who is experiencing psychosis may incorrectly believe a family member is trying to harm or even kill him/her.

Personality changes are quite common with HD, and family members may be embarrassed to admit that their once calm and reasonable loved one is exhibiting out-of-control behavior.

Sometimes, things reach the point of extreme crisis before family members call for help.

One of the most important things to remember is that this is the DISEASE, not the person, talking and acting irrationally and aggressively. Remind family members of this fact, too!

If at all possible, avoid using handcuffs or any type of restraints.

If you cannot reach the caregiver or a family member, and the person is not safe to be released, send him/her to a hospital ER or a psychiatric receiving facility. Make sure that you share information about Huntington's disease with them as it is very possible that they are not familiar with the disease.



Challenges in Late Stage HD

Vicki Wheelock, MD



Late Stage Challenges:

Usually a long time from diagnosis to death and that can be and IS exhausting for the person and family.

Disease Progression



Unawareness of symptoms or limitations, Mood symptoms, cognitive decline.



Loss of independence and funtionality.

HD person isn't the person they once were and it is hard to process and watch that for family.

Support



Often needs 24/7 care and may require out of home care which is a difficult and emotional transition for everybody involved.



<u>CURATIVE Care</u>: This is the START of a disease process, recognizing changes and seeking medical assessment, diagnosis, treatment, medical intervention.

Hospice agencies can provide bereavement & grief support to ANYONE regardless of whether enrolled in Hospice.

Curative
Care

Hospice
Care

Death and bereavement
Care

PALLIATIVE Care: CAN be started at time of diagnosis OR at any time in disease process. Palliative care is an approach or concept to care that focuses on the WHOLE person (physical, medical, spiritual/faith, quality of life, family, persons values, etc) and QUALITY of LIFE and will include medical care, however has focus on pain management, minimizing symptoms, stress management, information, education and support (social, faith, spiritual.) Explores future planning and needs preparation. Can include community organizations, health systems, faith communities, family/friends. Its NOT often one organization, its multiple organizations working together to assist with the care and needs of the person.

HOSPICE care: Introduced in final stages of disease progression (i.e. bed bound/mostly bed bound, significant weight loss, recurrent infections – pneumonia, urinary tract, recurrent skin breakdown, other serious illness identified). Very similar to Palliative Care, provides similar services that will be focused on comfort, dignity and grief during the dying process. Focus on safe and comfortable environment, life closure and grief support for person and family.



Late Stage Care Considerations

Grief

- Most HD persons will retain some awareness of who they are, their family, past accomplishments, etc.
- Many will experience grief/loss through symptoms like sadness, depression, crying, frustration, agitation, anger, etc.
- May experience more difficult transitioning to facility environment/staff.
- Include spiritual or faith based support, as appropriate. (i.e. hospice, faith community.)
- Medication may be needed to help manage mood symptoms.

Medication

- Give consistently
- Contact HD team if medication doesn't seem to be working as well or changes in symptoms.

Sleep

- HD can cause sleep disturbances
- Having a sleep schedule—same time to bed and awake, no t.v./electronics 1 hour before bed, no caffeine after 1pm. Sleep at night and awake in the daytime.
- May need medication to manage

Nutritional Needs (Weight Loss)

- May need smaller and more frequent meals
- May need to change consistency of food to soft, moist or pureed food to minimize choking or coughing.
- IF not able to maintain adequate nutrition , ask about the option of a feeding tube.

Equipment

- Adaptive equipment: walker, bathroom/shower grab bars, wheelchair, hoyer lift, bed.
- Custom wheelchairs needed to accommodate postures and movements of late-stage HD. (Broda chairs cushioned tilt in space wheelchair, etc)
- Specialized bed/recliner, bed on floor, communication device, special utensils, low flow drinking cups, etc
- Padded furniture and equipment to prevent injury and bruising. (i.e. bumpers/pillows, etc)
- Seatbelts, seat vests, pummel seats



Care Considerations (cont.):

Establish Daily or Weekly Schedule

- Identify the CONSISTENT staff for the various activities bathing, medication, exercise.
- Set DAILY schedules (bath on Monday, meals @ 8, 12 and 5, etc)
- Hang SCHEDULE and plan where it is readily seen.

Communication

- May experience harder time talking or finding the right words
- May be harder for others to understand
- Utilize picture boards, communication devices as need.

Pain

- May include skin breakdown or sores (reposition frequently if laying or sitting)
- Often unable to express pain with words or pain level
- May show discomfort or pain with restlessness, change in behavior
- IF a symptom/issue (bruising, skin sores, etc) would trigger pain for others, it is likely HD persons will also have, but may be unable to express it.
- Acetaminophen, Ibprofen can be sufficient for most aches and pain.
- Massage, stretching range of motion exercises may help.

Bathroom Difficulties

- Consider a bathroom schedule (i.e. in attempt to "train" bladder or bowels to go at certain times; try to go every 2-3 hours regardless of urge)
- Introduce briefs or pads at night, during travel outside of home or at home to minimize accidents. (can wear briefs AND use bathroom, get pull up kind).

Death with Dignity, Euthanasia, Physician Assisted Suicide: often times persons with HD will ask about their end of life options or right to terminate their life when they are ready and that is OKAY. Currently in the U.S. some states do have laws for this, however each State requirements will vary. This area is everchanging and options & laws change, therefore IF this is something you want to discuss, please bring up with your HD team and we would be happy to engage in discussion around options, laws at that time.

Body, Brain and Organ Donation — unfortunately it is not possible to participate in all 3 of these options after death. Therefore, it is important for you to discuss your after death wishes with your family so you can plan, register and make arrangements to honor your wishes.

Organ Donation

Organ donation is gifting your organ to a person that needs this organ for medical reasons

Donate Life California

Golden State Donor Services

California Transplant
Donor Network

Brain Donation

Brain donation will be used for research purposes specifically for HD.

Does require preregistration as there are specific time frames to recovery the brain after death.

HD Legacy -- Harvard Brain Tissue Resource Center

Body Donation

Body donation is used for medical study & teaching of students and staff regarding learning parts of body, procedures, etc

Often referred to as Willed Body Donation

Most medical schools have a body donation option.



Additional Questions or Support

For additional support, questions or to discuss late stage care needs, options, etc please contact your <u>HD care team or nearest HD Social Worker</u>. Any questions, needs or discussions are important, and we are happy to discuss with you.



Mid to Late Stage HD Resources

Lisa Kjer-Mooney, LCSW

Home Health

Home health care services provide a wide range of medical services in a home setting such as physical therapy, speech therapy, occupational therapy, medication assistance, nursing services, etc. Home health is short term and is covered by most health insurances as ordered by a physician. Please contact your insurance provider for a list of Home Health Agencies contracted for your insurance.

City	Name	Contact Information	Website
Nationwide	National Association for Home Care & Hospice	202-547-7424	Website will allow you to search for Home Care and Hospice Agencies in your area. Visit the website and choose the <i>Agency Locator</i> tab. www.nahc.org
Nationwide	U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services	7500 Security Blvd. Baltimore, MD 21244- 1850 800-633-4227	Website will provide you will information and resources regarding Medicare eligibility and providers. Once on the website, go to Resource Locator tab and select Home Health Agencies to start the search. www.medicare.gov
Statewide	California Association for Health Care Services at Home	3780 Rosin Ct, Suite 190 Sacramento, 95834 866-422-4724	www.cahsah.org

Hospice

Hospice care offers services and therapies to patients that are terminally ill and want to remain at home at the end of life. Hospice care strives to ensure the comfort of the patient and family at end of life. Hospice teams consist of hospice MD, nurses, social workers, chaplains, and volunteers. The role of hospice is to address medical, nursing, psychological, social and spiritual needs for both the patient and family. Hospice is covered by most health insurances, however, does not provide 24 hour direct caregiving to patients.

City	Name	Contact Information	Website
Nationwide	Hospice Directory	800-854-3402	Website will allow you to search for local hospice agencies in your area. www.hospicedirectory.org
Nationwide	National Association for Home Care & Hospice	202-547-7424	Website will allow you to search for Home Care and Hospice Agencies in your area. Visit the website and choose the <i>Agency Locator</i> tab. www.nahc.org
Statewide	California Association for Health Care Services at Home	3780 Rosin Ct, Suite 190 Sacramento, 95834 866-422-4724	www.cahsah.org
Additional	Home	000 122 1721	

Additional Resources:

HDSA.org HDSA

HDSA Center of Excellence, UC Davis HD Social Worker

Internet Searches on Willed Body, Brain Donation and Organ Donation





Finding Long Term Care

Lisa Kjer-Mooney, LCSW

Recognizing that you need additional care in the home and/or need to find out of home placement can be a long, difficult and emotional process for all members of the family. It can be challenging to find local facilities that can meet the care needs or are willing to accept an HD person. Emotionally, it can be a time filled with guilt, sadness, grief, fear and anxiety for all family members including the HD person. It is NEVER easy to accept help or move a loved one, however is often necessary for the well-being and safety of the entire family. The first step to is to plan early. Do not wait until you need assistance or placement to begin your search.

What kind of care is needed?

- •In home care
- Out of home placement

What does the person need help with?

- Dressing
- Bathing
- Eating
- •Meal Preparation
- Medication management
- Toileting
- •Grooming, etc

How will the care be paid for?

- Privately/Out of Pocket
- •Long Term Care insurance
- •Medi-Cal

Costs of Long Term Care (Monthly): Genworth Cost of Care Survey for California 2020 https://www.genworth.com/aging-and-you/finances/cost-of-care.html Costs will vary by location.

In Home Assistance

• \$5,529 per month

Adult Day Health Care

• \$1,733 per month

Out of Home Placement

- Assisted Living \$5,000+ per month (depends on care needs)
- Nursing Home \$9,247+ per month



Types of In-Home Care & Out of Home Placement

In Home Assistance

- Paid privately or by long term care
- Provides "custodial" care services
- dressing, bathing, grooming, toileting, bathing, meal prepartation, light housekeeping, transportation, household shopping, companionship, etc
- •cost is by the hour and usually has a per day or week minimum

Home Health/Hospice

- 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

In Home Support Services (IHSS)

- 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

Residential Care Facility/Board and Care Home

•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.

Assisted Living

•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.

Skilled Nursing Facilities

 offer 24 hour personal and medical nursing care for persons unable to care for their own needs and safely be independent.

Things to CONSIDER when finding CARE

What is the current and past BEHAVIOR of the HD person?

Do they have Psychiatric history? History of Aggression?

Are the behaviors stable and managed with medication?



Caregivers and care facilities must weigh the risks of caring for a person with current and/or history of psychiatric, behavioral or aggressive symptoms. This does not mean they will not be accepted, care may take longer to secure

Steps to Planning Early:

How will care be paid for? (Privately, Medi-Cal, Long-Term Care Inurance)

Find the care options in your area.

(Senior or In Home assistance care, placement agencies, etc) Gather & keep UP TO DATE medical documentation to share as needed.

(current medications, insurance card, medical provider contacts, etc.

Follow Up with Potential Providers:

In Home

- do interviews to ensure the provider is a good fit for your needs.
- Sometimes it can be hard to KEEP caregivers, so don't get discouraged if they don't stay long term.

Out of Home **Placement**

- Contact facilities periodically to see bed availability.
- Placement is about timing and they may be full one day and have availability the next.
- Be patient and persistent

Medical Care

 Continue to get your loved one medically evaluated to keep the medical documentation up to date.

Transitioning from family care to hired caregivers:

Introduce the new caregiver(s) to the **HD** person BEFORE they start caring for them.

Initially caregiver should do mostly "hands off" (housekeeping, meal prep, etc)care to let HD person get familiar with their presence.

Build Rapport & Trust with HD person by asking questions about hobbies, family, past stories

Transitioning from Home to Facility:



"I don't want to go"

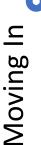
- Rarely do HD persons choose to go to facility on their own.
- They will likely constantly ask to "go home", if this happens assure them they are safe and getting good care and you will visit often.
- Try to distract loved one from this topic, sharing stories, going for walk, etc.



Family Feelings about move

grief, guilt, sadness, anxiety, relief, etc are NORMAL feelings family members have when placing a love one. Placement will allow you to move from nurse (make sure they bathe, eat, brush teeth, etc) to

- you to move from nurse (make sure they bathe, eat, brush teeth, etc) to spending quality time holding hands, talking, watching t.v., etc.
- Set up visitation schedule that is realistic
- Share written resources with facility about HD so they get more understanding of HD.



put familiar items (pictures, blankets, music, decorations) in the room for added comfort.

- Consider having favorite foods/drinks available.
- Coordinate with care staff how to help your loved one be most comfortable (food, t.v. shows, etc)
- Some facilities will allow residents to leave with family for holidays, special events.

Finding resources in your area:

Medicare California for Nursing Home Reform (CANHR)

HD Support Groups HD Social Worker Area Agency On Aging

Internet search for the service you are looking for



Care Resources: In Home & Out of Home

Lisa Kjer-Mooney, LCSW

Adult Day Health Care

Adult Day Health Care (ADHC) is licensed community-based day care programs offering services such as medical services, physical therapy, occupational therapy, speech therapy, personal care services, social services, nutritional counseling, meals while at the center. Some facilities may offer transportation to and from center as well. ADHC services are either paid by Long Term Care Insurance or privately. Medi-Cal recipients may qualify under the Community Based Adult Services (CBAS) program. Please contact the center directly for specific services and payment options.

County/City	Name	Contact Information	Website
Statewide	Department of Aging, Area Agency on Aging (AAA)	800-510-2020	https://www.aging.ca.gov/Find Services in My County/My County/?cc=4
Statewide	Cal Quality Care.org		https://www.caregiver.org/state- resource/calqualitycareorg/
Statewide	Department of Social Services	This website allows you to search for a variety of licensed care facilities in your agency. Facilities you can search for include: Adult Day Care, child care, residential care, transitional housing, etc. https://www.cdss.ca.gov/inforesources/community-care-licensing/facility-search-welcome	

In-Home Assistance

In-home assistance consists of companionship, housekeeping, cooking, personal care (dressing, grooming, bathing, etc), and grocery shopping. This service is usually provided on an hourly basis and is not covered by most health insurances. (Medi-Cal patients can apply for In Home Support Services (IHSS) which provides the above services.) Most in home assistance agencies will charge by the hour; rates range between \$25--\$35 per hour and may have a 3-4 hour minimum, however the rate and minimum number of hours varies by agency. For additional in-home assistance providers in your area you may do a search of Eldercare Home Health Services or In Home Assistance. Due to constant changes with website addresses and change in contact numbers, I have just listed a few agencies that other HD families have used in past.

<u>In a second sec</u>	
City	Name
Sacramento	Therapeutic Interventions
Sacramento	Griswold Home Care
Sacramento	Creative Solutions in Elder Care
Sacramento (Greater Sac	Craig Cares
area)	
Sacramento (Greater Sac	Welcome Home Care
area)	
Sacramento, Lodi and East	California CareGivers
Bay	
San Francisco Bay Area	California CareGivers
Statewide	Area Agency on Aging (AAA)
	https://www.aging.ca.gov/Find Services in My County/My County/?cc=4
Statewide	California Department of Social Services In Home Support Services (IHSS)
	https://www.cdss.ca.gov/in-home-supportive-services



https://health.ucdavis.edu/huntingtons/

We do not have any "HD facilities" in California, any facility CAN take HD persons, however they may choose not to take HD persons.

Assisted Living

For persons with independence & need daily supervision/ assistance

Room or apartment-style accommodations

Base Services: meals, social activites, internet, cleaning etc Add on services: bathing, grooming, feeding, toileting, medication

Residential Care

also called Board & Care: residential homes (5-7 residents), on-site 24 hour supervision/care

Provides all care needs: meals, medication, bathing, toileting, medication management, etc.

may also provide socialization, exercise and recreational activities

Skilled Nursing Home

24 hour personal and medical nursing care

Short term rehabilitation AFTER hospitalization -- person plans to return home

Long term care for patients that are no longer able to live in an independent environment

Locating Facilities in Your Area

Placement Agencies and Search Sites below can help you find facilities in your area.

City	Name	Website
Statewide	Department of Aging, Area Agency on Aging (AAA)	https://www.aging.ca.gov/Find Services in My County/My County/?cc=4
Statewide	Cal Quality Care.org	https://www.caregiver.org/state-resource/calqualitycareorg/
Statewide	Department of Social Services	https://www.cdss.ca.gov/inforesources/community-care-licensing/facility-search-welcome
Statewide	California Advocates for Nursing Home Reform (CANHR)	Website offers information about licensed Skilled Nursing Facilities as well as Assisted Living & Residential Care Facilities in California. CANHR also has information on complaints filed against any licensed facilities for your review. www.canhr.org
Statewide	California Association of Health Facilities (CAHF)	http://cahf.org
Statewide	California Registry	Website offers information about licensed care facilities (Assisted, Residential and SNF) in California. www.calregistry.com
Nationwide	U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services	www.medicare.gov

OUT of STATE Facilities specializing in HD

Listed below are facilities throughout the United States that are reported to have HD units and/or specialize in caring for HD persons. Please contact the facility directly for eligibility, cost and other questions.

State	Name	Contact Information	
Connecticut	Fresh River Health Care	860-623-9846	
Indiana	Summerfield Health Care Center, Cloverdale	765-795-4260	
Indiana	Byron Health Center	Sarah Starcher-Lane, HFA 12101 Lima Rd Fort Wayne, IN 46818 260-637-3166 ext. 226	
Indiana	Hanover Nursing	410 W Lagrange Rd Hanover, IN 47243 812-866-2625	
lowa	Zearing Health Care Center HD Program/Care Beyond Home	404 E Garfield St. Zearing, IA 50278 641-487-7631	
Massachusetts	Braintree Manor Healthcare	1102 Washington Street Braintree, MA 02184 781-848-3100	
Massachusetts	Kindred Healthcare	Needham, MA 02494 508-930-3780	
Massachusetts	Tweksbury Hospital	Tweksbury, MA 01876 978-851-7321	
Minnesota	University Good Samaritan Center	Minneapolis, MN 612-673-6260	
Missouri	Sunset Healthcare	Union, MO	
New Jersey	JFK Hartwyck at Cedar Brook	Karen Petrin 1340 Park Avenue Plainfield, NJ 07060 908-754-3100	
New Jersey	Leisure Chateau	Lakwood, NJ 732-370-8600	
New York	Terrence Cardinal Cooke	New York, NY 212-360-3711	
New York	Sitrin	2050 Tilden Ave New Hartford, NY 13413 888-578-8807	
New York	Victoria Homes	25 N. Malcolm St Ossining, NY 10562 914-487-4644	
New York	Archcare at Ferncliff	Rhinebeck, NY 12572 845-876-2011	
Ohio	Westlake Rehab	Westlake, OH 440-892-2100	
Vermont	Crescent Manor	Burlington, VT 802-447-1501	
Washington	Bailey Boushay	End of life only in Seattle, WA	



Living with HD

Terry Tempkin, Nurse Practitioner Lisa Mooney, LCSW

Living with HD both as a person with HD symptoms and caring for HD loved ones at can have some challenges, however there are some strategies to increase safety and independence. As the disease progresses, you will need to adjust the living environment to meet the needs of the HD person as well as minimize the difficulty on other family in the home. Any change or increase in needs within the home can feel very stressful and overwhelming and can trigger changes in the HD person and care partner such as sadness/depression, anxiety, irritability, stress, decline in health, and changes in physical abilities, etc. HOWEVER, sometimes small changes or adjustments can help make things easier and/or safer which we will share some possible ways here.



SAFETY ASSESSMENT OF THE HOME

Consider ways to make home safer and more user friendly for HD persons to remain independent for as long as possible. Things to consider:

MOBILITY & BEDROOM

- Safe to go up/downstairs
- Do they have to use stairs in daily routine?
- Are there tripping hazards (rugs, coffee/end tables, small steps into other areas of home)
- Access to lighting, turn on/off when needed
- Is the home wheelchair/walker friendly?

BATHROOM

- Accessible with walker/wheelchair
- Handrails/grab bars
- Accessible so they can reach sink, brush teeth, comb hair

KITCHEN & MEALS

- Can they get food/drink safely for themselves?
- Ability to safely cook
- Breakable or non-breakable dishes

COMMUNICATION

- Telephone accessible
- Able to use telephone (dial)
- Can voice assistance devices be helpful

QUALITY OF LIFE

- Access to tv, music, computer, video games
- Comfortable/safe chairs for sitting, eating
- Safe accessibility to outdoor space

EQUIPMENT & TECHNOLOGY

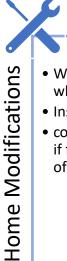
- Wheelchairs, Walkers, Hospital Bed, Hoyer Lift
- Smart Home Technology to monitor when care providers not around



MOBILITY & BEDROOM: below are some tips and tricks that may help minimize falls, make your home more accessible as disease progresses and assist with monitoring safety of the HD person when home alone.



- Fall Hazards:
 - remove throw rugs
 - remove furniture, not secured against wall.
 - stairs -- use handrails and avoid if unsafe.
 - place bed against wall and anchor for stability
 - increase lighting on strairs, hallways, rooms.
- Sleep Hygiene for quality sleep
 - avoid afternoon caffeine
 - go to bed and wake around same time each day
 - LIMIT t.v/electronics in bedroom



Widen doorways for wheelchair/walker

- Install ramps
- consider FLOOR bed if frequent falls out of bed occur.



Technology & Equipment

- Hospital Bed
- Hoyer Lift
- Motion Detection Video/Alerts
- GPS Tracking
- smart door locks
- Motion sensor lights, night lights



KITCHEN & MEALS: below are suggestions can help minimize choking/coughing, minimize injury and create a simplified and safer kitchen/mealtime environment.



Minimize injury/accidents

- Non breakable dishes
- avoid lifting pots with hot items
- electric stove instead of gas
- Microwave cooking instead of stove/oven

Minimize choking/coughing

- cups with lids & straws
- minimize distractions when eating
- consistent textures



Organize so that daily items are more easily accessible.

- wider pathways for wheelchair/walker
- lower counters for easier access in wheelchair



Equipment

Ø

Technology

Dishes with raised edges, compartments

- non slip materials under bowls/plates to avoid slipping
- Weighted utensils
- Pro-Vale drinking cups -slows down the flow into the mouth
- Lift Ware utensils
- Meal delivery
- Meal delivery kits

BATHROOM: below are some suggestions to minimize injury/falls, increase independence of personal needs and/or create a more accessible bathroom as care needs increase.

Minimize injury/accidents

- cordless razors
- no electric appliances around sink or tub -too easy to drop
- secure nail clipper to block of wood to stabilize & easier trim nails
- electric toothbrush remove obstacles in

bathroom

- throw rugs, baskets, extra furniture.
- toilet paper holders Bowel/Bladder Control
 - toliet every 2 hours

expand to allow for wheelchair/walker

- walk in tub/shower for wheelchair/walker
- additional people when assistance is needed

Bathroom Modifications

• remove sliding shower doors, high sided tubs

shower/tub chair for bathing

- grab bars -- shower area and toilet
- hand held nozzle
- good lighting in daytime and nightime
- motion detection lights or night lights are helpful

access • enough space for 1-2 Ø

COMMUNICATION: Due to cognitive changes with HD it can be a challenge for HD persons to communicate in some ways, these suggestions may help minimize miscommunication/frustrations, increase independence and/or create a simplified routine.

make eve contact to get their attention before talking

- speak facing the person so they can see your face and expressions --this helps with processing the words
- be aware of NON verbal ques (looks of confusion, anxiety, frustration, blank gaze, etc)
- distraction free environment (no t.v., music, other people talking)
- allow time for HD persons to respond, they will need longer.
- Establish signals for yes/no
- Yes/No questions or questions with 1-2 word responses

Technology & Equipment

communication boards

Equipment

Technology

- computer or phone applications to point to needs, feelings to express self w/out speaking
- modified telephone, larger numbers/keyboard, etc.

Voice assistance technology

- Voice assistive devices or video chat has proven to be beneficial in addressing social isolation, lonliness, and desire to maintain relationships.
- make it easier to manage t.v., electronics, music, phone, lights, door locks, appliances and thermostat.
- Can provide reminders for medication, exercise, appointments, etc.

Simplify and Create Routine

QUALITY OF LIFE: this is for the person with HD and anyone else living in the home. These suggestions are compiled to assist in creating a routine that is consistent and simplified to minimize stress, frustration, anxiety, etc. and hopeful increase quality of life and quality time together. HD is not easy and it's not realistic to avoid all challenges and difficulties, but sometimes it is small things that can make a big difference.

Technology & Resources



- Set up household calendar with activities, appointments, chore assignments all planned out!
- choose meaninful and enjoyable activities -- if it causes too much stress find another activity or ask for help
- Exercise for routine, physical and mental health
- Have activities to look forward too.
- Take family/friends/neighbors up on offers to help (mow lawn, fix-it needs, transportation, respite, etc)
- Use shared applications/calendars to ask for help or let others sign up to give breaks, plan activities, etc.



Smart Home Technology

- what if technology turned the t.v. on/off, and lights turned themselves on -- would that make life easier?
- Cleaning Service -- one less thing to worry about.
- Grocery/Household Items delivery -another thing to not have "to-do"

Where to find more information about Living with HD

Talk with your HD care team or HDSA Social Worker about your specific needs and recommendations.

Q Internet Search: Smart Home
Caregiving Technology, Home
Modifications other ideas to utilize
technology in your home for safety.

AARP https://www.aarp.org/caregiving/

- How to Make your Home Safer: practical tips for home safety and utilizing smart technology.
- Home safety checklist: helpful in assessing home safety.

HD Support
Groups (Video or InPerson) others in
similar situations
share techniques,
equipment and/or
ideas that worked

well for their family.

HDSA: www.hdsa.org

HD Presentation @ 2018
 National Convention discussing
 Smart Home Technology had
 some really good ideas from an
 HD Care Partner.

HDSA Publications:

- Physical and Occupational Therapy – Family Guide Series
- Caregiver Guide for Mid to Late Stage Huntington's Disease – recommend pages 34-69.

TIPS THAT COULD HELP KEEP YOUR LOVED ONES SAFE:

- Purchase a smoking apron to prevent your loved one from getting burned.
- Buy lighters, not matches.
- Swimming noodles work well for padding different shaped areas.
- Use medical straps to help secure your loved one from falling out of chairs. NEVER LEAVE YOUR LOVED ONE UNATTENDED WHEN USING A MEDICAL STRAP.





Ideas On Ways to Safe Proof Your House For Your Loved One Living With Huntington's Disease

Help 4 HD International Inc.
423 West Ocean Ave.
Lompoc, CA 93436
www.help4hd.org
916-698-0462

Bedroom

- It's best to place the mattress on the floor so your loved one doesn't fall off the bed while sleeping.
- Remove all wall décor that is glass in case it gets knocked off the wall, or make sure they are securely fastened to the wall in the case your loved one runs into them.
- Remove all rugs; they can be a tripping hazard for someone with HD.
- Remove all bedside tables.
- Remove all free standing mirrors, lamps, or things that can be knocked over and cause injury.
- Cover sharp edges of dressers and other bedroom furniture in case your loved one falls into the furniture.
- Use mattress covers in case of spills or accidents.
- Make downstairs as comfortable as
 possible to encourage your loved one
 not to try to go upstairs. If the bedroom
 is upstairs, make sure to have a proper
 secure railing for your loved one.



Kitchen

- Remove knobs from oven and stove, especially gas stoves, when you are not using them.
- Keep sharp objects such as knives, can openers, and any other utensils that can injure your loved ones safely out of reach.
- Replace glassware with plastic kitchen plates, cups, bowls, etc.
- Remove any food or beverages that come in glass containers to plastic containers.
- Put cleaning supplies in a locked cabinet.
- Instead of glassware, use plastic reusable water cups with lids and straws to prevent spills and possibly help prevent choking.



Living Room/Family Room

- Remove coffee and end tables; this type of furniture can cause injury
- Place couches in front of windows; this way if your loved one falls, he/ she falls onto the couch, not through a window.
- Cover sharp corners like tile fireplace mantels.
- Try to avoid leaving shoes, clothes, toys, etc. on the floor for your loved one to trip over.
- You may want to consider buying furniture covers to protect your furniture from spills or accidents.
- Be careful of free standing lamps, fans, or decorations.
- Make sure all chairs and furniture are stable. No swivel chairs, rocking chairs, etc.



Bathroom

- Place grab bars in the shower as well as around the bathroom.
- Add a no-slip mat inside the shower or bathtub.
- Sturdy, no-slip shower chairs work great for an individual who can wash him/herself.
- Use padding between the wall and the toilet tank to keep the tank from breaking or from busting through the drywall if your loved one rears back.
- Raised toilet seat attachments will help the individual safely get on and off a toilet.
- Put padding around the lid of the inside of the toilet seat to protect the individual's back.





HUNTINGTON'S DISEASE SOCIETY OF AMERICA NORTHERN CALIFORNIA CHAPTER

Chapter Officers
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President

Martha Lehman Vice President

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Lisa Mooney, LCSW
lkjer@hdsa.org

Advisory Board Suketu Khandhar, MD Lisa Mooney, LCSW Jan Nolta, Ph.D. Vicki Wheelock, MD

National Office Louise Vetter, CEO (800) 345-HDSA(4372) www.hdsa.org

Regional Director Denny Cone dcone@hdsa.org

Chapter Website
http://.northernca.hdsa.org

Dear HD Family,

Our mission is to improve the lives of everyone affected by Huntington's disease and their families. We provide *help for today and hope for tomorrow*. We offer services and support to our families and stay informed on the latest HD research worldwide.

It is important that hope remains alive to move forward with a meaningful life. Through our special services, the chapter strives to make the journeys for HD families a little easier.

Here is a list of family services and events provided free of charge:

- Support Groups: in person and virtual
- Supports the HDSA Centers of Excellence in Northern California
- Provides a Helpline answered by an HD specialized, licensed social worker
- Makes available educational in-services to nursing homes
- Organizes an Annual Chapter Education Day with workshops and research updates
- Publishes a periodical Chapter Newsletter
- Participates in Legislative Advocacy and HD Awareness
- Participates in the annual National HDSA convention (scholarships available).

We hope you will get involved. You are welcome at any support group, chapter event or fundraiser! If you are interested in volunteering or board membership, please let me know. Dates and locations for all support groups & events are posted on the chapter website. Please email the chapter or me to be added to our mailing list. It is free and confidential.

Hope to meet you soon!

Warmest regards,

Dawn Green
President, HDSA Northern California Chapter dlgreen5@comcast.net

About the Northern California Chapter:

Since 1970, HDSA Northern California Chapter has been committed to providing support and information to HD families. In Northern California there are an estimated 1,300 people with HD and another 6,500 people at-risk. Our board is made up of volunteers, who are dedicated to helping HD families. Nationally, HDSA is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's Disease from community services and education to advocacy and research.

HDSA Northern California Chapter PO Box 5365 San Mateo, CA 94402 Social Worker Helpline: (916) 734-6277



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.



HD In Person -group meets at central
location. Contact Lisa
Mooney, Social
Worker @
lkjer@hdsa.org for a
recent group listing



HD Video Support
Groups -www.supportgroups
central.com/hdsa



HD Social Media Groups

Facebook, Twitter, etc
These may NOT be
professionally
monitored so please
use caution when
seeking
advice/recommendati
ons and always discuss
issues/concerns with
your medical team.



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.



General Caregiver
Support, CA
Caregiver
Resource Centers:
https://www.caregiver.org/californias
-caregiverresource-centers

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



Tel: 916-938-3576

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

•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.

Assisted Living

•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.

Skilled Nursing Facilities

 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

- Paid privately or by long term care
- Provides "custodial" care services
- dressing, bathing, grooming, toileting, bathing, meal prepartation, 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.

Home Health/Hospice

- 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.

In Home Support Services (IHSS)

- 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.

Tel: 916-938-3576

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



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

HDSA



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

Help4HD



1-800-273-8255; http://suicidepreve ntionlifeline.org/

Lifeline

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



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

HD Research

HDSA supports the goals of clinical, translational and basic research aimed at developing treatments and, ultimately, a cure for HD by supporting leading research facilities globally. HDSA has committed tens of millions of dollars to fund research with the goal of finding effective treatments to pave the way to a world free of HD.

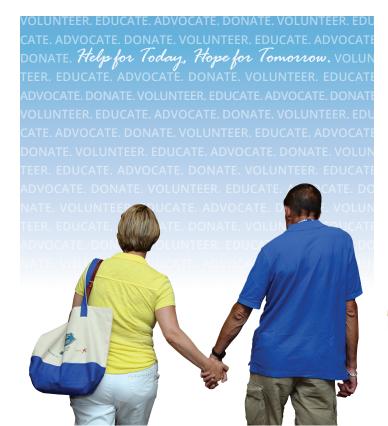
Each year, HDSA supports a wide range of research programs & services:

- Berman/Topper HD Career Development Fellowship
- HD Human Biology Project
- Donald A. King HD Research Fellowships
- HDSA Monthly Webinars
- HD News Mobile App
- HD TrialFinder Call Center & clinical trial search tool

The most critical component of HD research is clinical trial involvement. Without clinical trials there will be no treatments for HD. Please visit www.HDTrialFinder.org for more info on HD clinical trials in your area.

Advocacy

Through the work of our Advocacy program, HDSA has seen the passage of the Genetic Information Nondiscrimination Act (GINA) and added HD & JHD to the Social Security Administration's Compassionate Allowances List. The work of our ever-growing network of dedicated advocates includes supporting the Huntington's Disease Parity Act, a bill that will help people with HD access crucial Disability, Social Security & Medicare benefits.



In the battle against
Huntington's disease,
no one fights alone.
At HDSA,
family is everything.

Volunteer. Educate. Advocate. Donate.

Your generous donation and your time will directly impact the lives of HD families. Join the fight against Huntington's disease in your community by visiting www.hdsa.org or call (800) 345-HDSA.



505 Eighth Avenue, Suite 902, New York, NY 10018 (800)345-HDSA | www.hdsa.org





(800)345-HDSA | www.hdsa.org



About HDSA

The Huntington's Disease Society of America is the premier not-for-profit organization dedicated to improving the lives of everyone affected by Huntington's disease.

From community services and education to advocacy and research, HDSA is the world's leader in providing *help for today, hope for tomorrow* for people with Huntington's disease and their families.

Across the United States, HDSA currently supports:

- 50+ Volunteer-led Chapters & Affiliates
- HD Research
- HDSA Centers of Excellence
- Social Workers
- Support Groups
- Education Programs
- Advocacy Efforts
- Extensive Community Education & Awareness through Team Hope Walks and more than 200 Special Events

HDSA was founded in 1967 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.



What is Huntington's Disease?

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. HD deteriorates a person's physical and mental abilities during their prime working years and currently has no cure.

Many describe the symptoms of HD as having ALS, Parkinson's and Alzheimer's disease – **simultaneously**. Over time, HD affects the individual's ability to reason, walk and speak. Symptoms usually appear between the ages of 30 to 50, and worsen over a 10 to 25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure or other complications.

The gene that leads to HD was identified by researchers in 1993. Every person who inherits the expanded HD gene will eventually develop the disease.

Symptoms include:

- Personality changes, mood swings & depression
- Forgetfulness & impaired judgment
- Unsteady gait & involuntary movements (chorea)
- Slurred speech, difficulty in swallowing & significant weight loss

Nearly 10% of individuals with HD develop symptoms before the age of 20. Juvenile HD (JHD) typically progresses more rapidly than adult HD.

The Quintessential Family Disease

Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes HD. If the child has not inherited this expanded gene, he or she will never develop the disease and cannot pass it on to their children.

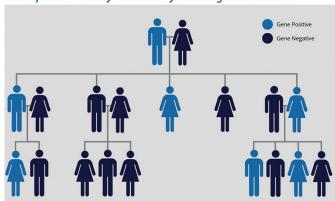
Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

HD Care

Within a family, multiple generations may have inherited the disease. Those at-risk may experience tremendous stress from the uncertainty and sense of responsibility. Lack of knowledge about HD in a community may keep friends and neighbors from offering social and emotional support to the family, fostering unnecessary isolation.

HDSA has a nationwide network that provides support and referrals for individuals with HD and their families through support groups, educational programs and the signature HDSA Centers of Excellence which provide multidisciplinary HD care.

Example of a family affected by Huntington's disease.



What is Huntington's Disease

Huntington's disease (HD) is a hereditary neuro - degenerative brain disease. Every child of an HD individual has a 50/50 chance of inheriting the same fate. HD is a trinucleotide repeat disorder where the mutated gene causes unstable CAG (cytosine-adenine-guanine) expansion.

Every individual has a CAG repeat, but the normal range is 10-26. An individual with a CAG repeat >38 will have Huntington's disease at some time in their lifetime. The gene was discovered in 1993 and a diagnostic genetic blood test was developed.

The juvenile form of Huntington's disease (JHD) is more progressive and virulent. JHD children represent about 5% of all HD cases and are diagnosed with family history, a CAG of >60 repeats and diagnosed before the age of 20. Symptoms include: uncontrolled movements called chorea, decline in scholastics, memory loss, psychiatric behaviors, seizures, dystonia, loss of balance and tremors to name a few.

HD and JHD individuals eventually lose their ability to take care of their own needs and become completely dependent on caregivers for everything. Care of HD individuals is extremely challenging and requires many disciplines. Mortality typically ranges between 10- 20 years for HD and less for JHD's, about 5-10 years after diagnosis.

For more information...

Contact us or donate to:

Help 4 HD International 423 West Ocean Ave. Lompoc, CA 93436

info@help4hd.org

Visit us on the web: www.Help4HD.org

PLACE STAMP HERE

Help 4 HD International Inc.

WHO IS



HELP 4 HD WEB-SUITE

Help4HD.org

Help4JHD

H4HDiRegister

Help4HD Radio

Research4HD

TheHuntingtonsPost

Help 4 HD

Who is Help 4 HD International?



Help 4 HD International Inc. was founded in 2010 by Melissa Biliardi when her son James was diagnosed with Huntington's disease. They reside in Santa Maria, California on the Central Coast. Help4HD was incorporated and tax exempt as a 501c3

Public Charity in 2013 and serves the Huntington's Disease (HD), and Juvenile Huntington's Disease (JHD) community.

Help4HD is a grassroots patient advocacy organization which utilizes multimedia communications and social media to propel its education and advocacy mission. Help4HD events, conferences and support groups inform and inspire the Huntington's disease community.

Help4HD Radio hosted by Katie Jackson goes Live every week. Go to BlogTalkRadio.com/ Help4HD for more information . More than 225 episodes also available on iTunes.com/Help4HD.

Help4HD Support Groups are in California and Florida. For more information, please visit ww.help4hd.org and proceed to the support group tab for information and locations.

Caring 4 HD Affordability Shop & Resource Center: The aim is to provide low cost household items, clothing, and medical equipment for families in need. The Resource Center will provide information about community services, clinical trials, social services and caregiver resources available to our HD families as well. Come and shop or donate your no longer wanted items. Plus It's always fun to shop at the Affordability Shop! You never know what treasures you'll find...

Mission

Help4HD's mission is to educate the world about Huntington's disease through its multimedia communications platform, and to find the underserved HD families who are seeking information, education and resources. All HD families need help with the challenges that are thrown in their path; many find themselves in crisis situations. The goal is to discover the underserved areas and bring support and resources to those who need help.

COMMITMENT TO SERVE

All of Help4HD's amazing staff and volunteers have the same desire to help and serve. Each, have a strong connection to HD and JHD and understand the burdens that all HD families face.

Help4HD is committed to its caregiver support and education initiatives providing information about research and clinical trials, connecting credible care professionals with the community is top priority. Now with several Help4HD support groups and chapters, what started out as a California Central Coast Association, has become a global community outreach and effort.

Help4HD's 100 Global Ambassadors are working every day to bring advocacy and awareness about HD and JHD to the world. Please contact our founder, Melissa Biliardi if you would like to join our Ambassador team. We are eager to work with you!

Contact: Katie Jackson, Help4HD International Office: 916-698-0462



(left) Katie Jackson President, Help4HD

(right) Katrina Hamel Vice President of Operations, Help4HD



President, Katie Jackson, husband Michael and their amazing children. Mike was diagnosed in 2007. Their children have a 50/50 chance of inheriting the same fate.

Family First!

Help4HD is focused on helping HD families by bridging communications and partnering with institutions, industry, and professionals from every discipline. Help4HD's philosophy is "Family First". Nothing is more important than facilitating safe and healthy families and the way we do that is through education and support services. Here is what one medical professional says about Help4HD:

"Help 4 HD International has been able to reach a portion of the Huntington's community that no one else has" Dr. LaVonne Goodman, Seattle WA

HELP4HD's SUPER SIX

- 1. Communications
- 2. Education
- 3. Events & Conferences
- 4. Fundraising Initiatives
- 5. Patient Advocacy
- 6. Support Services



FOR KIDS

This section, particularly geared towards our younger readers and their parents, includes games that test your HD knowledge, as well as narratives that help kids understand HD, such as "Bryan's Dad has HD" and "Gensen, the Runaway Gene".

HOPES NEWS

This section includes updates on what HOPES team members are doing and current research in the HD world.

ABOUT HOPES

HOPES is a team of faculty and undergraduate students at Stanford University dedicated to making scientific information about Huntington's disease (HD) more readily accessible to the public.

We emphasize that we are neither medical professionals, nor affiliates of the researchers and laboratories mentioned on our pages. The information we present is intended for educational purposes only and should not be construed as offering diagnoses or recommendations.

HUNTINGTON'S OUTREACH PROJECT FOR EDUCATION AT STANFORD

http://hopes.stanford.edu

HD BASICS

Huntington's disease (HD) is a neurodegenerative disease; symptoms are caused by the death of nerve cells in the brain. Symptoms typically begin between the ages of 30-50, though juvenile HD begins in childhood or adolescence. The disease is caused by a mutation in the DNA: an extended CAG repeat in the huntingtin gene, which creates a mutant protein that damages and kills neurons. This mutation is dominant, so people with HD have a 50-50 chance of passing it on each time they have a child. Symptoms are motor (related to movement), cognitive (related to thoughts), and behavioral.

HD AND THE BRAIN

The brain is made up of many parts, but the region most affected by HD is the striatum, which is responsible for controlling our movements. HD is similar to other neurodegenerative diseases, such as Alzheimer's and Parkinson's which also cause brain cells to sicken and die. There are many theories as to how the mutant huntingtin protein causes neuron damage, and a better understanding of the neurobiology of the disease might help lead to a cure.

HD RESEARCH

There is a lot of research on how HD affects the brain and how it could be treated. Lately, stem cells have shown particular promise with treating HD. Mesenchymal stem cells, which are adult cells in the bone marrow that eventually turn into bone or fat cells, may be used in the future as a potential HD treatment as they release neurotrophic factors in the brain, which assist in the growth of new neurons, repairing the degeneration caused by HD.

HD GENETICS

HD is a genetic disease; it is caused by a glitch in the huntingtin gene. Genes are made of DNA, the biological 'blueprint' that makes us who we are. The information contained in DNA is translated into proteins, which perform many of the roles in the cells of the body. When the DNA transcript is wrong, the resulting protein can lose its ability to work properly and can even become harmful. This is the case in HD, where the huntingtin gene has too many CAG repeats and gets translated to a protein with a long sticky tail of glutamine. These proteins clump together and interfere with the important processes that go on in our brain cells.

MANAGING HD

HD presents many difficulties and lifestyle changes, and there is no one way to manage the disease. For instance, some children of HD parents choose to be tested for the disease before symptoms occur, to see whether they have inherited the disease. Others choose not to be tested for a variety of reasons. For those that have the disease, diet, exercise, and sleep are all very important, and a healthy lifestyle makes symptoms easier to live with.

DRUGS AND SUPPLEMENTS

There are many drugs and supplements that have the potential to treat symptoms of HD, and might even slow the course of the disease. These treatments are in various stages of testing, from studies on mice all the way to clinical trials where hundreds of people with HD take the drug. The only FDA approved drug specifically meant to treat HD is tetrabenazine, which treats the uncontrollable, jerky movements (called chorea) associated with HD. Scientists are actively studying certain supplements, like creatine and Coenzyme Q10, that might prevent some of the damage HD causes to the brain.

HD IN A NUTSHELL



Caring for a Loved One with HD: Self-Care for Family Caregivers

Lisa Kjer-Mooney, LCSW

Caring for a loved one with a chronic illness such as HD can be both physically and emotionally demanding. The combination of loss, prolonged stress, the physical demands of caregiving, and the emotional aspects can place caregivers at risk for significant health problems. Caring for somebody is never easy and is not without challenges and difficulties, but there are strategies and specific actions you can take to prevent negative consequences to your physical and emotional health.



Caregivers are less likely to engage in preventive health behaviors.⁴

23% of family caregivers caring for a loved one for 5 years or more report their health as fair or poor. ²

Estimates show that between 40-70% of caregivers have clinically significant symptoms of depression⁶

Specifically, HD caregivers also had diminished health related quality of life with 43% reporting that they were dissatisfied with their overall quality of life.³

These statistics are not meant to discourage, but rather demonstrate the negative impacts caregiving can have if you do not adequately care for yourself. Our hope is this will encourage you, as a caregiver, to take your health and well-being seriously so you can remain healthy to care for your HD loved ones. If you are struggling to manage any of the symptoms below please consider talking with you doctor AND incorporating some of the strategies in this document.



NEGATIVE symptoms impacting Physical and Emotional Health

Physical Symptoms

- ✓ Health decline (frequently sick or under the weather)
- ✓ Sleep deprivation
- ✓ Exhaustion
- ✓ Changes in appetite or weight
- √ Failure to exercise
- ✓ Putting off or failing to attend medical appointments
- Excessive alcohol, tobacco, drug use

Emotional Symptoms

- ✓ Overwhelming stress
- ✓ Prolonged sadness
- ✓ Depression
- ✓ Guilt
- ✓ Anger
- ✓ Grief
- ✓ Frustration
- ✓ Anxiety
- ✓ Social isolation or withdrawal



https://health.ucdavis.edu/huntingtons/

Self-Care Strategies

Educate & Plan

- Learn about HD and how to realistically plan.
- Know your finances
- Discuss healthcare wishes (Advanced Care Planning)
- Identify available community resources
- Engage family/friends in developing a caregiving plan.
- Arrange backup caregiving that is regular and dependable.
- Get organized:
 - Have list of doctors, medication and medical history up to date and readily available.

Improve Communication

- Use "I" statements rather than "you" statements to express feelings: "I feel angry" verses "you make me angry"
- Respect the feelings of others, even if they differ from you.
- Avoid intentionally hurtful comments to others
- Allow others to express their feelings as well
- Be clear and specific about what you need or want
- Actively listen
- Be honest and genuine in your communication with others.

Exercise

- Daily exercise for best results
- Finding time can be difficult, but walking, stretching, etc is effective and may be easier to incorporate into your day.
 - Walk around your neighborhood, mall, to the store or a nearby park
- Find physical activities you enjoy (online, videos, in-person, exercise clubs, etc)

Stress Management Techniques

- Identify areas of stress that you can change and areas you cannot change.
- Use team approach to accomplish daily tasks: Ask friends/neighbors to assist with mowing lawn, transporting children, raking leaves, etc.
- Continue to participate in enjoyable activities.
- Find reasons to laugh.
- Utilize relaxation methods: yoga, meditation, deep breathing, sleeping, reading, bubble baths, creative activities--painting, writing, drawing, arts and crafts, scrapbooking, etc. and outdoor activities (gardening, walking, etc.) can all be therapeutic in reducing stress.



organizations, etc.

- Identify your social and community support
- Participate in HD support groups (inperson or video)
- Utilize any respite services as needed
- Get recommendations on available resources and support from others

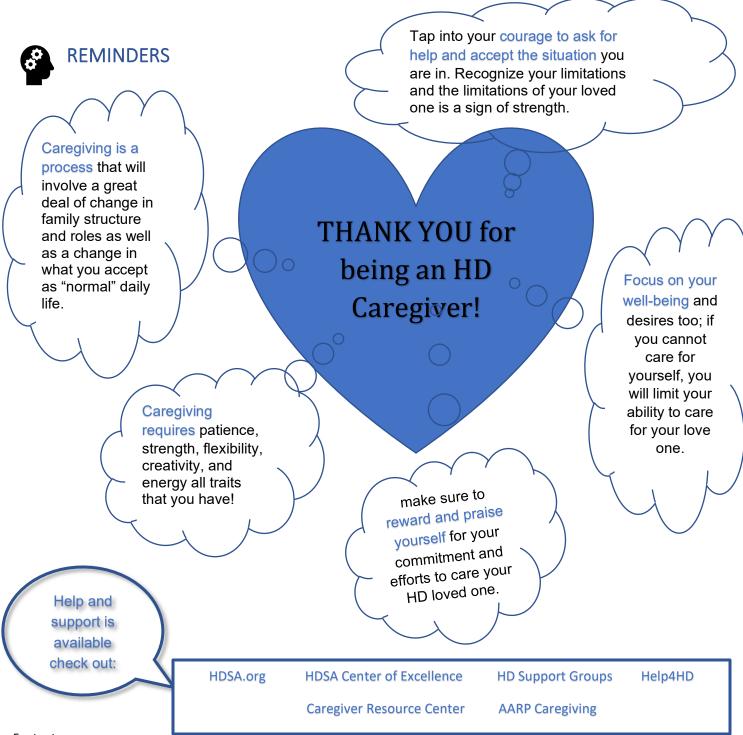


Ask For & Accept Help

 Others often want to help but are unsure of what is needed or most helpful.

Prepare a list of ways others can help (write, electronic, etc): ideas: transportation, walking the dog, mowing the lawn, putting out the trash, preparing meals, assist with completing/mailing forms, keeping patient company while you away.

- Resist asking the same person repeatedly
- Be specific and direct with your requests
- When someone offers help say "yes" and refer to your list.



Footnotes

² Caring in the U.S.; National Alliance for Caregiving in Collaboration with AARP, November 2009

³ Dorey, J, Cohen, J Mraidi, M, Urbinati, D, Toumi, M, Burden of Huntington's Disease in the USA, Poster 186 presented at the World Congress on Huntington's Disease, Melbourne, Australia, 11-14 September, 2011.

⁴ Family Caregiver Alliance, Caregiver Health, http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822

⁶ Family Caregiver Alliance, Caregiver Health, http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822



Talking to Your Loved One's Doctors

Strategies for Successful Communication

Vicki Wheelock, MD

Working with medical providers for the care and management of HD will be important. We hope this will help you share information with providers that may not be familiar with HD as well as tips and strategies to have difficult discussions and how to ask for what you need.

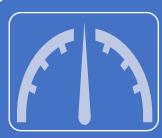


Anticipating Transitions, the challenges and the needs:



Healthy to Early HD

- may have changes in work, home performance
- changes in relationships
- Mood changes
- may need help with identifying changes and next steps



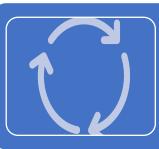
Early to Mid Stage HD

- May need to explore DISABILITY/Retirement options -- can be frustrating and challenging
- Discussions of driving safety
- May need more supervision, oversight or reminders for everyday tasks/responsibilities.



Late Stage HD

- often needs 24/7 care
- may need out of home care
- may need to get more family or hired help involved



Common challenges

- Unawareness of symptoms -- may not think they are experiencing changes, may not recognize the severity or intensity of symptoms, etc
- Mood symptoms can be unpredictable and often arise without warning
- Strong desire to maintain independence may impede cooperation or seeking assistance.





Caregivers are ESSENTIAL to Living Well with HD

Help with setting up safe and successful home/work environments

Help manage, plan and organize responsibilities (fill our forms, get medical visits scheduled, etc)

Essential to the communication to Medical Providers what is changing

Essential to maintain socialization for HD person.

Improve the overall quality of life for HD loved ones.

Caregivers NEED care too! Seek help & support early.

Where to go for care? HD specific care will be best addressed at a HDSA Center of Excellence or local Neurologist familiar with HD. You do not need to determine IF something is HD related or not, if you have questions call your Primary care psychian or HD team to discuss to determine what provider is best to address the concern.







HDSA Center of Excellence -health centers that meet
criteria as experienced,
knowledable and having an
interdisciplinary team
approcah to care and
treament of HD. Please see
HDSA.org for a current list
of HDSA Centers of
Excellence's.

Local Neurologist -- can be a local option for more urgent or frequent care as needed in between visits

Primary Care Physician
(PCP) -- every person should
maintain contact with a
local PCP for health related
needs. Can be a place to
get referral to HDSA Center
of Excellence for HD care
when ready.

the visit.

Be Seen & Heard — time with medical providers is often limited so being prepared and ready to share your information confidently and efficiently will be the most effective approach to get the most benefit out of

Communicate what you see, observe and experience on a daily basis with your loved ones providers

Use e-mail, medical chart communication, video or phone to communicate with your loved ones providers.



Encourage your loved one to attend REGULAR medical visits: every 6 months to 12 month or more frequently if things are changing.

Write down & Share



- Questions as they arise to refer back to at appointments
- List of dates, symptoms, frequency to share with provider
- Note when you shared a new symptom with provider and the recommendation
- Current medications, dosages, prescribing provider AND list of past medications and when they stopped and any side effects.
- KEEP list of doctors, providers, important numbers, Advance Directives, etc. all in ONE place to grab and share as medical care is needed.

At visits:



- Ask your questions
- Prioritize and share most challenging or bothersome symptoms.
- Ask for actions, recommendations & secure follow up appointments BEFORE leaving the visit.
- Ask for referrals for Physical, Occupational, Speech, Dietician, psychiatry, as you feel is needed.

Creating a Medical and HD Care Kit: As HD progresses there may come a time of crisis when family or friends have to assume care of you or your HD loved one. Others may need to communicate with first responders, medical professionals, law enforcement, etc about you or your HD loved ones needs. In order to avoid additional stressors or crisis, it is helpful to have a Medical or HD care kit readily available to assist in maintaining appropriate care even in a crisis or unpredictable situation. This "kit" can be a digital file, binder with print outs or handwritten notebook but will contain important information about you or your HD loved one regarding your medical history, medications, care needs, medical providers, etc.

- List of Emergency Numbers (family, friends, neighbors, medical providers)
- Medical Summary (updated every few months) of current symptoms (mood, cognitive changes, surgical history, hospitalizations, etc)
- Recent picture and physical description
- Important Documents (copies of birth certificate, marriage license, conservatiorship/guardian, Advance Directive, Living Will, Trusts, bank accounts)
- Copy of Medical insurance cards
- Copy of Identification or Driver's License
- Copies of medical documentation/notes or how to access the records digitally.
- List of Medications, dosage, reason for taking the medication and any allergies or side effects from past medications.
- Any other information that will be helpful for others in urgent or emergency situations

This will take work, time and effort to create however can be helpful in keeping organized and others informed of important information

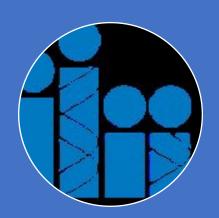
- Some people will include personal things like likes or dislikes that can be helpful in comforting a person in times of stress or crisis.
- There are smart device applications or websites that can assist in getting something like this created. Use caution if sharing your medical information online.

Where to find information, written materials or ask questions



HD Social Worker

- You don't have to be followed at a HDSA Center of Excellence to speak with an HD social worker. Please visit HDSA.org to find the social worker nearest to you.
- The social worker can help with problem solving, connecting with resources or answering HD questions.



HDSA

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



Help4HD

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

Remember, you are NOT alone! There is care and support available.

Caring for other is HARD and cannot be done alone. If you have questions, concerns or are struggling with something please reach out for assistance. It takes a village, as "they" say!



Caregiver Hacks

Gathered by: Lisa Mooney, LCSW

When caring for an HD loved one, if often seems like simple tasks can be a challenge. This document shares hacks, ideas and strategies other HD families have shared as ways to help them in their caregiver responsibilities. Please review the *Living with HD* section for additional information about adjustments in environment for added safety and independence.



Simplify your life....(or at least try!)

Motion Technology

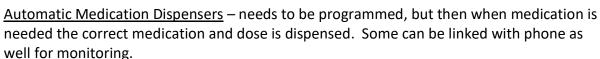
- Smart Home Technology to monitor when care providers not around. Can hook up camera's inside, outside and on doors to alert you (via phone) that someone is around your home.
 - This is helpful for those that are HIGH Fall risk and don't stay still.
- Wearable Trackers on body, clothes, shoes some even have GPS can be helpful if your HD loved one is still mobile or driving so you can locate them as needed.





Medication

<u>Bubble pack medication</u> – some pharmacies can put all the morning, evening, daily medications into a bubble pack that then the HD person can push open for all the medications.



Manual Medication Organizers



Getting Help

- Shared calendar, document or phone apps where family/friends CAN sign up and help.
 - You can put what you need: (Sitting with your loved one, grocery shopping, transportation, household chores, yard work, etc) and they can do it for you.
- Find ways to take things OFF you List....
 - Cleaning Service
 - Grocery/Household Items Delivery
 - Meal Delivery Service –you can get meals to prepare or meals already cooked so just heat and serve.











Voice Assistance Technology



Tel: 916-938-3576

- Voice assistive devices, phone or video chat has proven to be beneficial in addressing social isolation, loneliness, and desire to maintain relationships.
 - Can be used to set reminders for your HD person on when to take medication or shower, when to eat lunch, when to exercise, or upcoming appointments, etc.
 - Voice Assistance have "drop in" features so you don't have to call but can communicate with your HD loved one without them using phone.
 - Can be used to turn on/off t.v., electronics, music, phone, lights, door locks, appliances and thermostat.



QUALITY OF LIFE

- Explore meaningful and enjoyable activities you can do together as family
 - Movie nights, watch family videos/photos together



- o some HD families have found that Train travel allows them enjoy travel with their HD person.
- Schedule an exercise routine this will help with physical and mental health. Even short 5 minute walk outdoors can be beneficial. Put it in the schedule so it has a better chance of getting done.
- Stretches/Deep breathing during t.v. commercials, when in car on way to new location (quick ones can be found on internet)



Where to find more information about Living with HD

Talk with your HD care team or HDSA Social Worker about your specific needs and recommendations.

Q Internet Search: for other ideas...

- Smart Home Caregiving Technology,
- Caregiving Hacks
- Meditations/Deep Breathing
- **Quick Stretches**
- Stress Management

AARP

https://www.aarp.org/caregiving/

Lots of tips, hacks, and recommendations for caregivers regarding home safety, self-care and utilizing technology.

HD Support Groups (Video or In-

Person) others in similar situations share techniques, equipment and/or ideas that worked well for their family.

HDSA: www.hdsa.org

HD Presentation @ 2018 **National Convention discussing** Smart Home Technology had some really good ideas from an HD Care Partner.

HDSA Publications:

- Physical and Occupational Therapy – Family Guide Series
- Caregiver Guide for Mid to Late Stage Huntington's Disease recommend pages 34-69.



Caregiver Resources

Lisa Kjer-Mooney, LCSW

Support Groups:

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 to meet your needs.



2 Local Caregiver HD Groups

Contact Lisa Mooney, Social Worker @ Ikjer@hdsa.org for a recent group listing



HDSA Caregiver Video Support Groups -www.heypeers.com



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.



General Caregiver
Support, CA Caregiver
Resource Centers:
https://www.caregiver.o
rg/californias-caregiverresource-centers

Caregiver and Respite Resources

California Caregiver Resource Centers

services are free or low cost and include:

- Education
- Respite Care
- Information and Referral
- Family Consultations
- Care Planning
- Short-Term Counseling
- Support Groups
- Legal and Financial Consultation

https://www.caregiver.org/resource/californias-caregiver-resource-centers/



Respite

Community respite programs are limited, but may be available through

- Assisted Living or Memory Care Facilities for a daily fee.
- California Caregiver Resources
 Centers
- National Organization for Rare Diseases (NORD), see brochure in this section.
- For those caring for persons with developmental delays as well – Regional Centers, UCPsacto.org may be able to assist.



Counseling/Therapy

Participation in therapy and counseling can be very beneficial and assist with coping, problem solving, communication, grief/loss, stress management and much more. There are many types of counselors/therapists (LCSW, MFT, Psychologist, etc) and you will need to choose a therapist that you trust and are comfortable with.

Where to start?

Insurance: Call you insurance provider to see if they have Behavioral Health resources that you can utilize.

Employee Assistance Program (EAP): Many employers have Employee Assistance Programs which can offer short term counseling as well as other benefits.

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







Individual one on one counseling

Couples/Family

will involve the couple or entire family unit in the counseling process

TeleTherapy

or also called Telehealth many different options available, this is done via video, telephone or even text.

Group Therapy

often offered based on a need (depression, trauma, anxiety, etc); lasts 6-8 weeks in length with other persons also looking to find support for that need.

HD Support Groups

these are not "therapy", but offer a safe space to express self, find understanding and get support from others in similar situations.

Additional Resources

UC Davis HDSA Center of Excellence

California Caregiver Resource Centers

AARP Caregiving

County Behavioral Health Departments

CAREGIVERS, FIND RELIEF



Rare Caregiver Respite Program



This first-of-its-kind assistance program is designed for caregivers (parent, spouse, family member, or significant other) of a child or adult diagnosed with a rare disorder. NORD understands that caring for a loved one is a generous gift that demands significant amounts of time, attention, patience and dedication.

The Respite Program provides financial assistance to enable the caregiver a break to attend a conference, event or simply have an afternoon or evening away from caregiving. Financial assistance will be granted up to \$500 annually for those who qualify. Awards may be spread throughout the year or in a single use.

Alone we are rare. Together we are strong.

What care may be covered?

- Registered Nurse (RN)
- Licensed Practical Nurse (LPN)
- · Certified Nursing Assistant (CNA)
- · Home Health Aide (HHA)

Who is eligible?

- The caregiver must be a US citizen or permanent resident of the United States for at least 6 months with evidence of residency
- The applicant must be willing to undergo a financial evaluation of need and fall within the Program's financial eligibility guidelines
- The patient for whom care is being provided must have a confirmed rare disease diagnosis

How do you apply?

Awards are granted on a first come, first served basis to eligible individuals. A NORD Patient Services Representative will guide the applicant through the process, including verifying financial eligibility using our Electronic Income Verification System.

The application decision process can take as few as five minutes over the telephone. Applications completed and submitted via email, fax or US mail will be processed within three business days of receipt. There is no fee to apply.



FOR MORE INFORMATION ABOUT THIS PROGRAM, CONTACT NORD AT:

203.616.4328 or email CaregiverRespite@rarediseases.org

Donations to NORD for this and other programs may be made by contacting orphan@rarediseases.org.

NORD: Fighting for the rare community every day for more than 35 years.

NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research and patient support services.

NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians.

NORD Headquarters: 55 Kenosia Avenue, Danbury, CT 06810 Tel: 203.744.0100 Fax: 203.263.9938 ©2019 NORD. All rights reserved. NORD®, its icon and tagline are registered trademarks of The National Organization for Rare Disorders. NORD is a 501(c)(3) charity organization. NRD-1182



rarediseases.org



Communicating with Youth about HD

Lisa Mooney, LCSW

Open communication is essential for healthy relationships, growth, understanding and knowledge. Communication can be verbal, written and non-verbal through emotions, reactions, facial expressions and behavior. Outlined below is information about engaging in discussion and on-going communication with your children about the Huntington's Disease diagnosis in the family. Good communication with your children can assist all members of the family in coping and dealing with the changes and loss that will occur over time. Allowing children to discuss HD will prepare children to best cope with the changes and losses that may lie ahead. As the children age their cognitive skills will develop and they will be able to better understand the information being discussed.



Who, How, When & the Why on talking to kids?

WHO

- It is important to make sure the child is familiar and comfortable with the person who is sharing information
- The person must be knowledgeable and have correct information about HD
- IF the HD person can participate, they should
- Other persons can include, non-HD parent, close family member, close friend, or professional healthcare provider

WHEN

- Children should be told at all ages as close to initial diagnosis as possible.
- The earlier you talk about HD the more normal and comfortable it will be for you and the child.
- It is never too early to tell the children
- there is never a "right time".

HOW

- Environment should be comfortable, familiar and safe with minimal distraction, so you and the child are free to express your feelings honestly.
- Understand that the initial conversations may be uncomfortable for you and the children and will likely get easier as the foundation for open communication is established.
- Remember that you will need to talk to different age children separately as they will have different questions, concerns and reactions.
- Be present and prepared to spend the necessary time to needed to address any questions or feelings.

WHY

- Children are great observers and can often sense when something has happened through your facial expressions, behavior and emotions.
- If children need answers and don't feel they can get them from family, they will get them from outside sources and risk getting incorrect information.
- Remember, it takes a lot of energy to "hide the truth."
- Fear is learned
- By not discussing the diagnosis children will learn to fear HD and potentially the person with HD.



Keys to the discussion

Honest & Genuine

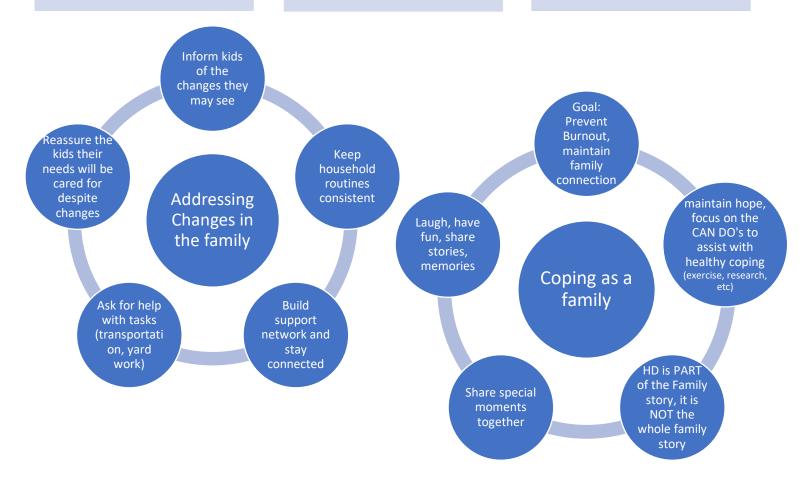
- Children need to know you will ALWAYS tell them the truth
- •They will likely pay more attention to your emotions and actions more than the words.
- Demonstrate there is no shame or secrecy in discussing HD or their feelings
- Share your feelings, fears or concerns with them (age appropriate of course)
- •Only make promises you can keep

Information Sharing

- Share age appropriate information using words they understand
- •Be comfortable saying "I don't know", "HD is confusing, complex and sometimes difficult to understand" so "let's find out the answer together"
- •Assure them that you will share information as you get it.
- Provide space and offer to discuss whatever they need in the future
- Don't assume children are too young for information, if they ask find an age appropriate way to discuss

Active Listening/Allow for Silence

- •Let child direct the conversation as they will ASK what they need to know.
- Respect what the child has to say
- •address all their questions
- acknowledge their feelings
- •give time to process the information and feelings
- •may need to schedule a follow up conversation



Different Ages and Stages

Age 0-2 (Babies & Toddlers)

Children at this age sense your feelings and react to your emotional state.

 behavior, appetite and sleep may change, and developmental milestones may be delayed due to feeling anxious or depressed.

Interact with:

- soothing voice
- hugs and affection
- patience

Intense discussions or arguments should not take place in front of children this age.

 They will not understand what is being said but will definitely react to how you are feeling.

Ages 2-5

(Preschoolers)

Tell them small bits of information, define the illness

Mom/Dad has an illness called Huntington's Disease.

Allow them to ask questions if they have them, answer with simple, brief explanations.

Children of this age may experience:

- anxiety
- changes in behavior, sleeping (nightmares) or attachment fears when leaving caregiver
- feelings received from non-verbal communication

Keep routines as consistent as possible.

Ages 5-12 (School Age)

Can be overly concerned about health

- Do not overwhelm with details of appointments as they may worry about them to the point they may become ill
 - Share outcome of MD appoints "I had an appointment today and the MD says I'm doing well!"

Let the school/teachers know what is happening

 They can be part of the child's support while not with the family.

Children of this age may experience changes in:

- Eating
- Sleeping (nightmares)
- Anxiety about leaving caregivers, going to school
- changes in school performance
- Social withdrawal, changes in friendships
- Regression to bed wetting, sucking thumb, etc.

Provide children with attention and affection.

Ages 13-17 (Teenagers)

Children of this age are prone to mood swings, anxiety and depression (w/out presence of illness in family) and this may increase with the HD information.

Confusion between wanting to be independent, yet still dependent on adults.

 Not sure how to handle their own emotions.

Teens may express anger and withdraw when HD is discussed.

AND

Teens may seek support from outside family (peers, teachers, etc.)

Assure them any feelings they are having are natural, normal responses.

https://health.ucdavis.edu/huntingtons/

Age 0-2	Ages 2-5	Ages 5-12	Ages 13-17 (Teenagers)	
(Babies & Toddlers)	(Preschoolers)	(School Age)		
	If they know what to expect they are better prepared to cope. • Function on day-to-day basis: tell children the schedule for the day.	They will need to feel included and aware of family situation/changes.	Provide information, allow them to ask questions and express their feelings when they are ready. • Provide written materials to support the information you are discussing.	
	Reassure them nothing they have done has caused HD or can change the situation. • Children at 4-5 may feel they have "magical" powers and if they wish for something (good or bad) it will come true.			

Discipline



https://health.ucdavis.edu/huntingtons/
Feelings and Emotions: If you are showing how you feel, children will feel more comfortable

expressing their feelings. If children do not learn to express themselves, they may become frightened of their strong emotions instead of accepting them. Children of all ages may experience:



be addressed if experienced over a prolonged period

NOT ALL IS BAD....

When faced with a challenging, life threatening illness like HD it is possible for children to grow in their ability to:

- Understand and accept another person, despite differences
- become more self confident and independent
- May learn to be more responsible and sensitive to others needs
- experience optimism and hope
- DO NOT UNDERESTIMATE and Child's ability to teach you how to adapt, cope and be positive in hard times.

References and Resources





Internet Resources for HD Youth

Lisa Kjer-Mooney, LCSW

Huntington's Disease Youth Organization (HDYO)	http://en.hdyo.org/	Offers support to young people with written resources, informative videos, personal stories, and activities and events for youth to help educate and cope with being part of an HD family.
Huntington's Disease Society of America (HDSA) National Youth Alliance (NYA)	http://hdsa.org/about- hdsa/national-youth-alliance/	The NYA's mission is to support young people within the HDSA community as well as inspire youth to get involved in the battle against HD.
Help 4 HD International	https://help4hd.org/	Help4HD's mission is to educate the world about HD through its multimedia communications platform and through community outreach efforts. They offer support groups, education events and resource programs to assist HD families.
HOPES for Kids	https://hopes.stanford.edu/for- kids/	Resources, activities designed for youth to assist in youth learning about HD.





About HDYO

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org

What is the HDYO?

The Huntington's Disease Youth Organization is an international non-profit organization set up to specifically provide support for young people around the world impacted by Huntington's disease.



How is HDYO run?

HDYO was founded and is run mostly by young people impacted by HD for other young people. Since launching in 2012, we have developed a team of over 170 volunteers in a variety of roles, who are almost all young people impacted by HD. Our roles include:

- The HDYO Board who oversee our organization
- Translation Team who make us multilingual
- Forum Moderators who respond to people in the forum
- HDYO Reps spreading positive HD awareness globally
- Feedback Team professionals who review our content

We also have two staff roles including the Project Coordinator and a Director of Youth Services.

What are HDYO's goals?

HDYO aims to provide support to young people (kids, teens and young adults) impacted by Huntington's disease around the world. We seek to drastically improve the amount of educational information provided to young people and their families with regards to Huntington's disease. Also, HDYO looks to improve support for young people both locally and globally, by collaborating with national Huntington's disease associations around the world to improve youth support in their area.

How was HDYO formed?



HDYO was officially launched on 7th February 2012, but the idea for HDYO began back in the summer of 2010. HDYO was first presented and discussed by its eventual founder, Matt Ellison, at the Young Adults Working Group for EHDN in 2010. The working group's task is to produce ways to improve support for young

adults impacted by the disease. The idea of HDYO received unanimous backing from those at the meeting and work began to make the idea a reality. From that meeting excitement spread and young people around the world began offering their services in order to help create HDYO. Many took the role of translators and began the massive task of translating material that was being created by HDYO. Others joined the HDYO Board to help assist in the planning of the HDYO project. It took over 18 months of hard work, collaboration, communication and determination to produce the end result of HDYO – an exciting, youthful organisation to support young people impacted by Huntington's disease.

How is HDYO funded?

The money to initially launch HDYO was raised by young people working on the project,

through various acts of fundraising. Now, HDYO is financially supported and backed by the Huntington's Disease Associations around the world - who each donate an annual sum to the HDYO cause, which enables HDYO to create more support, educational information and opportunities for young people impacted by HD around the world. We also receive grant funding to cover our staff roles and enable us to bring support events to various regions of the world.



This document was downloaded from the HDYO website at http://en.hdyo.org/eve/about/28

Advice received via the HDYO web site should not be relied upon for personal, medical, legal or financial decisions and you should consult an appropriate professional for specific advice tailored to your situation.

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http://hdyo.org





HDSA's National Youth Alliance (NYA) is a

sisterhood and brotherhood founded on the vision of becoming the last generation with Huntington's disease.

NYA Dav



gathering NYA members together to learn about

event is dedicated to

new issues that affect young people and brain-

storm how the NYA can work to positively

affect young people across the country.

The NYA is a network of children, teens and young adults between the ages of 9 to 29 from across the country who are impacted by Huntington's disease. The NYA motivates members to be proactive in their local HDSA Chapters, Affiliates and support groups in efforts to promote education, fundraising, advocacy and awareness for HD.

As an integral part of the future of HDSA, the NYA prides itself on their ability to persevere. Year after year, they continue their mission to support the HD youth community through local services and building life-changing relationships for the better, forever.

NYA Programs

Youth Retreats

NYA Youth Retreats provide young people around the country the opportunity to learn, grow and get to know other youth in their area who are affected by Huntington's disease, in a mini-camp atmosphere! All NYA Youth Retreats are free to attend!



Advocacy

The NYA gives young people an opportunity to raise their voices by training and mobilizing



young folks to be advocates for issues that affect families with HD! The NYA helps young people go on advocacy trips to Washington D.C., ensuring that people in power know how they can help families with Huntington's disease.

Convention Scholarships

The NYA provides scholarships to young people to attend HDSA's Annual



organized yearly by the NYA Board. The all-day

Annual Convention is

NYA Day at HDSA's

to attend HDSA's Annual
Convention. Through donations,
the NYA is able to send dozens
of young people each year

to this incredible event!



Huntington's What Is Disease?

of nerve cells in the brain. It deteriorates a person's physical and mental abilities and has disorder that causes the progressive breakdown no cure. Huntington's disease (HD) is a fatal genetic

symptoms of HD are described as having ALS, 30,000 symptomatic Americans and more than Huntington's disease. There are approximately chance of inheriting the gene that causes Parkinson's and Alzheimer's — simultaneously 200,000 at-risk of inheriting the disease. The Children of a parent with HD have a 50/50

swallowing & significant weight loss. swings & depression, forgetfulness & impaired Symptoms Include: personality changes, mood ments (chorea), slurred speech, difficulty in judgment, unsteady gait & involuntary move-

adolescents and JHD typically progresses more of 30 to 50, and worsen over a 10 to 25 year rapidly than adult onset HD Huntington's disease (JHD) affects children or period. In approximately 10% of cases, Juvenile Symptoms usually appear between the ages



Huntington's Disease
Society of America



NATIONAL YOUTH ALLIANCE Huntington's Disease Society of America To learn more, or to become involved contact us at:

Tel: 800.345.HDSA (4372)

Email: board@HDSANYA.org

Check out our website at www.HDSA.org/NYA







505 Eighth Avenue Suite 902 Huntington's Disease Society of America New York, NY 10018





Where to go for HD Resources

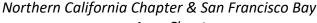
You are invited to explore the following organizations and websites for beneficial HD information, research, and education to the HD Community. Topics range from research, social support, resources, clinical care, genetic testing, how to talk to children and much more. There are written, verbal (podcasts) and visual (video) resources at all these sites.































HD Helpline: 916.938-3576 or lkjer@hdsa.org



HD Support Groups

For HD Persons:

California	Cathy Wang, Susan Reynolds & Lisa Mooney Ikjer@hdsa.org sreynolds@hdsa.org	3 rd Tuesday each month, 12:00 – 1:30pm
National	HD Social Workers	Varies check website for dates/times.

For HD Care Partner/Caregiver:

East Bay Caregivers	Natasha Boissier, LCSW <u>HDSAEastBayCaregivers</u> <u>@gmail.com</u>	4 th Tuesday each month 7pm -8:30pm
National	HD Social Workers	Varies, check www.HeyPeers.com for options and dates.

For ANY persons impacted by HD

Greater Sacramento Area	Lisa Mooney, LCSW <u>lkjer@hdsa.org</u> 916-938-3576	2 nd Wednesday each month, 7pm-8:30pm
Palo Alto	Satve Ilango, 650-587-0988 silango@hdsa.org	2 nd Tuesday each month, 7pm-8:30pm
National	HD Social Workers	Varies, check www.HeyPeers.com for options and dates.

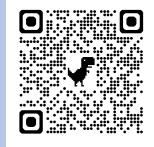
For persons that have lost a loved one to HD.

National	Amy Slavin, Elle Tadina-	4 th Tuesday each month,
	Siau, Susan Reynolds	12:00 – 1:00pm
	sreynolds@hdsa.org	
	aslavin@hdsa.org	

For Youth and Young Adults

	<u></u>	
National	HD Social Workers	Varies, check
		<u>www.HeyPeers.com</u> for options and dates.

All HD support groups are primarily VIDEO at this time. Please visit www.heypeers.com to join any HD support group.



HD Helpline 916.938-3576 or lkjer@hdsa.org





HD Books and Movies

Below is a list of books and movies with Huntington's Disease as the subject. This list is NOT exhaustive nor is it an endorsement that UC Davis HDSA Center of Excellence endorses the information, interventions, recommendations or feelings expressed in each book/movie. This is an informational resource so you may explore additional perspectives and information about HD. YouTube, Amazon and other internet searches will produce results that may have other book and movie options available.

Title	Author/Director	Overview
a Alive & Well	Josh Taft	Alive & Well is a powerful documentary film about the human condition, which follows seven resilient people coming to terms with the profound reality of living with the hereditary chronic illness known as Huntington's Disease (HD).
Bound for Glory –	Woody Guthrie	First published in 1943, this autobiography is also a superb
Autobiography		portrait of America's Depression years, by the folk singer, activist, and man who saw it all. Woody Guthrie was born in Oklahoma and traveled this whole country over—not by jet or motorcycle, but by boxcar, thumb, and foot. During the journey of discovery that was his life, he composed and sang words and music that have become a national heritage. His songs, however, are but part of his legacy. Behind him Woody Guthrie left a remarkable autobiography that vividly brings to life both his vibrant personality and a vision of America we cannot afford to let die.
Breaking the Cycle	Robert Rippberger	A documentary on Huntington's Disease, a family torn apart and how a bike ride and one courageous Matt Austin brings them together.
Can You Help Me?	Thomas Bird, MD	This book shares the surprising, insightful, challenging, and even encouraging stories of patients and their families who live with HD. Having seen patients for more than 40 years, Dr Thomas Bird, a pioneer neurogeneticist, adds a human touch to this genetic brain disease that devastates persons during midlife when they can least afford it. With a brief history of Huntington Disease and the occasional scientific detail, the true heart of the book is the human experience of the disorder in which some compelling stories of people of all ages and in all walks of life who feel trapped by a progressive degenerative brain disease from which there is no escape.
Dancing at the Vatican	Brian Moore	An emotionally charged, moving documentary about sufferers of the last 'hidden disease' on earth, authored by former Emmy award winning TV reporter Charles Sabine, following Huntington's Disease Patients from Latin America on a life changing journey to the Vatican and an audience with His Holiness Pope Francis.
Dancing with Elephants	Jarem Sawatsky	This book is about how he learned to accept his prognosis, and not live in fear of it, but rather to dance with the 'Elephant in the room'. The author imparts his learnings on how to accept the changes to his mind, body, and soul and endeavors to help the reader do the same.



Title	Author/Director	Overview
Faces of Huntington's	Carmen Leal-Pock	Faces of Huntington's is an incredible collection of stories, essays, poems, and quotes of those who are in some way connected to Huntington's Disease. The book focuses on over sixty people who have HD, are at risk, caregivers, other family members, and friends. It is a beacon of light in what is often a dark world. Somehow, despite the horror of Huntington's Disease, there is loving support, a positive attitude, and unending hope. There are stories that make you rejoice at the unswerving faith and those that make you cry at the senseless loss. Faces of Huntington's gives readers a glance at the faces of heroes. It is guaranteed to bring tears of joy, hope, love and compassion to your eyes.
Gene Hunter	Nancy Wexler	Nancy Wexler is the daughter of a Huntington's patient and is at risk for this disease. Finding this gene is a vital step toward preventing or curing Huntington's and thus saving lives. Nancy's work takes her all over the world, specifically to small villages in Venezuela where the mysterious gene affects more people than anywhere else on the globe. Blood samples generously donated by the villagers hold the clues to discovering the gene.



Title	Author/Director	Overview
Grandma Has Huntington's Disease and It's Okay	Dr. Kelsey M. Finn	This book tells the story of a grandmother who has Huntington's disease, a genetic condition, from the perspective of her grandson, Leo. This book is intended to serve as a way to communicate with children about HD, and help children understand what it means for them and their family member affected by HD.

Title	Author/Director	Overview
Her Mother's Daughter	Huntington's Disease Society of America, Rae Maxwell	Her Mother's Daughter, a film by Rae Maxwell and produced by HDSA, introduces the world to Kathi O'Donnell and shows the devastating impact that Huntington's disease (HD) & juvenile Huntington's disease (JHD) has had on the O'Donnell family. The film is a window into Kathi's inspiring journey as a caregiver as we see the different stages of HD & Juvenile Huntington's disease. Her Mother's Daughter is a powerful documentary of family, love and hope – across generations and against all odds.

Title	Author/Director	Overview
Huntington's Dance, The Film	Chris Furbee	In 1995, Chris Furbee received a distress call from his aunt: his mother, Rosemary needed immediate care. After many years with little contact with his family, Chris returned to the remote coal-mining town in his native West Virginia. Walking through the front door of his mother's house, Chris found a shocking sight. The house was turned upside down. Hundreds of partially smoked cigarettes, piles of trash & food were strewn about. It appeared that an emaciated stranger was lying on the couch, seemingly half-dead. After searching the house he discovered the person who was on the couch was in fact his mother. As the days unfolded, Chris realized that Rosemary was in complete denial of her condition. With few resources organized, Chris had to find ways to provide critical medical care for his mother who not only resented his help and felt he was meddling in her life but who also felt there was nothing wrong with her. Chris' coping mechanism was to set up a video camera in the dilapidated garage and share his deepest feelings of love, anger, and confusion. His thoughts about how to cope with the disease that he had run from years before were all captured on camera. From 1995 to the present, Chris chronicled his experiences in learning to cope with the potential hereditary nature of Huntington's Disease an illness that slowly eats away at your nervous system and your mind and in the process he created the documentary, Huntington's Dance.
Huntington's Disease & Me: A Guide for Young People	Alison Gray	Young people affected by Huntington's need to have correct and up to date information as early as possible young people want to know the truth and this must be provided in such a way that it is informative and factual, as well as supportive. With predictive testing available to those eighteen and over, the young must have this information early so that they have time to consider the implications of testing, not only on themselves, but also their family and friends. This book provides information about HD and offers strategies for coping with the immediate and long-term challenges. It is soundly based on the experiences of young people themselves. Some have just learned that HD is in their family, others are considering predictive testing themselves. Some have already experienced the loss of a parent. The Book shows that the experience of coping with HD is not all negative. Young People with HD families gain strength and courage. They learn to face the present and future with love, acceptance, compassion and hope. This book is an essential guide for that journey for both young people and adults.
Huntington's Disease Hero's	Foreword by Charles Sabine Edited by Erin Paterson	Inspiring stories of resilience from the HD community.



Title	Author/Director	Overview
	Jimmy Pollard	HD presents an ongoing series of challenges for all members of
Hurry Up & Wait	Jillilly Pollaru	the family. This book discusses exercises to simulate the
		cognitive difficulties faced by those with HD, a collection of tips
		to accommodate them in your home or care home, a strategy
		to develop new approaches to solving care problems and
		commentary on common problems faced by family caregivers
		and those they love.
L Eight for Understanding, 21	Ginnievive Patch	This book began as a series of tips on a Facebook page for
I Fight for Understanding: 31	(Author), Sharon	caregivers of people with HD/JHD. The roller coaster is a
Days of Coping With	McClellan	metaphor not just for the ups and downs of living with HD/JHD,
Huntington's Disease	Thomason	but also for the breakneck speed and unpredictability with
	(Editor,	which changes often occur. Just when you're riding along
	Illustrator,	smoothly, things begin to build up, and just when they reach
	Foreword)	their peak, you plunge with your loved one into the abyss that
	roiewoiu)	always seems to be waiting just over the top. But it doesn't end
		there. Everything levels out again, and you rock along, only to
		hit the rise, peak, and plunge once again. Over and over, you
		ride the roller coaster with your loved one who has HD/JHD,
		and every time, it can be just as scary and unpredictable as it
		was at the beginning of the ride because, you see, you never
	Alias Dataman	know what's coming around that blind corner!
If You Were Here	Alice Peterson	When her daughter Beth dies suddenly, Peggy Andrews is left
		to pick up the pieces and take care of her granddaughter Flo. But sorting through Beth's things reveals a secret never told:
		Beth was sick, with the same genetic condition that claimed her
		father's life, and now Peggy must decide whether to keep the
		secret or risk destroying her granddaughter's world.
1 . 2	Steven Beatty	This book is for those of us going through the "in-between
In-Between Years: Life after	Steven beatty	years": the years following our HD genetic testing, but before
a positive Huntington's Disease		the symptoms of the illness have begun to take hold. The years
test		when we may struggle with this look into the crystal ball we've
		been given, for whatever reasons are personal to us. The years
		when we symptom-hunt and worry about every forgotten
		purse and each trip and stumble. The years when we watch
		and care for other Huntington's disease affected loved ones
		and wonder, how long until it's our turn. How I coped with the
		present. Steven Beatty is part of a Huntington's disease family
		himself and received a positive result on his HD predictive
		genetic testing in 2015. Since that time, he has developed a
		passion directed at advocating for the Huntington's disease
		community



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Title	Author/Director	Overview
Inside the O'Briens: A Novel	Lisa Genova	Joe O'Brien is a forty-three-year-old police officer from the Irish Catholic neighborhood of Charlestown, Massachusetts. A devoted husband, proud father of four children in their twenties, and respected officer, Joe begins experiencing bouts of disorganized thinking, uncharacteristic temper outbursts, and strange, involuntary movements. He initially attributes these episodes to the stress of his job, but as these symptoms worsen, he agrees to see a neurologist and is handed a diagnosis that will change his and his family's lives forever: Huntington's disease.
It's a Bird	Steven Seagle	As comic writer Steve explores the myth and meaning of Superman for an undesirable assignment, he finds himself delving into some secrets of his own family along the way. A graphic novel that follows a young man and his feelings and experiences of Huntington's disease.
ELearning to Live with HD	Sandy Sulaiman	Learning to Live with Huntington's Disease is one family's poignant story of coping with the symptoms, the diagnosis and the effects of HD. This book presents the struggles and strengths of the whole family when one member loses their future to a terminal illness. Told by the sufferer and other significant family members, the individuals describe the burden of watching yourself and others for symptoms of HD, including involuntary movements, depression, clumsiness, weight loss, slurred speech and sometimes violent tendencies. The family recounts the challenge to remain united and describes how they approached issues such as whether or not to be tested for HD, how much information to disclose to relatives, whether to have children or not and guilt if one sibling inherits the illness and one does not. Both honest and positive, the author stresses the importance of re-inventing yourself and your present, prioritizing relationships and retaining a sense of humor.



Title	Author/Director	Overview
Elife Interrupted	Katie Lee Jackson, Vicki Owen, Pat Wolf, Sharon McClellan Thomason, Lisa Davenport, Ben Lamoreau, and Frances Saldana	Living the unimaginable, twelve Huntington's disease patients and caregivers share true stories of struggle, devastation, and life-shattering events as they travel the journey that is HD. Along the way, you'll meet ordinary people who develop extraordinary strength, courage, and perseverance as they try to counterbalance the chaos of lives falling apart as HD shows up like an out-of-control wrecking ball. One woman struggles for years to find her biological family, then discovers more than she expected. Agonizing parents watch helplessly as their children endure years of pain, lose every bit of their quality of life, and die far too soon, some from the juvenile form of HD. Couples fall in love, marry, and start their families just in time for this horrific disease to step in and rip everything away, eventually taking their soulmates' lives and leaving them with the knowledge that their children, too, may face the same terrible fate. Witness the strength of these families as they rise to the challenge and advocate to be the last generation ever to live with the horrors of Huntington's disease, a genetic neurodegenerative disease that has often been called the worst disease known to mankind.
Elife Interrupted, Part 2	Sharon McClellan Thomason, James Torrington Valvano, Ginnievive Patch, Stacey Sargent, Dorothy Gerber Pearce, Kinser Cancelmo, Terry Tempkin, Georgia Porter, Katrina Hamel, and Nancy Sweet	Life Interrupted, Volume 2, continues to tell the stories of people living with Huntington's and Juvenile Huntington's disease. From mothers who have lost their precious children to JHD and HD to patients who are living with HD, all are compelling stories of strength, perseverance, and courage. Some are caregivers for multiple generations; some didn't know about the disease being in the family until it struck with all its fierceness. All are stories of unbelievable struggle, loss, and hope.
Elivable Lives: Conversations with the Huntington's Disease Community	Christy Dearien	In Livable Lives, Christy Dearien tells her family's story along with stories from around the globe to explore how an incurable family disease impacts relationships, identity, major life decisions, and much more. In her conversations with the HD community, people talked about the importance of pursuing what one gene-positive young woman calls her "livable life" — a life lived with intention and meaning before symptoms begin. Fifty percent of the author's net proceeds will be donated to the Huntington's Disease Youth Organization.
Eliving with Huntington's Disease: What I've Learned as a Caregiver	Sharon McClellan Thomason	Huntington's disease (HD) has been called "the worst disease known to mankind." So what happens when your child, the person you love most in this world, is diagnosed with this monster? The author shares her experiences and what she's learned along the way, including how to advocate for your loved one and the grief and resilience that go hand-in-hand with living with HD.



Title	Author/Director	Overview
Eliving With Passion: A Young Woman's Huntington's Disease Journey to Truly Live with Passion	Alexandra Kathleen Boothby	My memoir is about me, a young woman who is living with a fatal neurodegenerative disease, Huntington's Disease, but doing so passionately. My goal is to choose happiness each day, and some days being happy is easier than others. My disease is only a part of my life, it's definitely, not my whole life. Being diagnosed with Huntington's Disease has positively affected my outlook on life and I strive to portray that in my memoir. I try to live in the moment, and live passionately, fearlessly, happily, and imperfectly. I would love for you to read my journey. I'm hoping it makes you have happy tears and that my Huntington's Disease will change your life for the better just as it with mine. My book helps people in the HD community to see a positive light in HD and it helps any one who is struggling with change and transitions.
Mapping Fate	Alice Wexler	This is an account of the how Huntington's disease affected one family. The author tells of how her mother died of the disease, how she herself stood a 50-50 chance of inheriting it, and how her sister and father sought first to find the gene and then find a cure.
MIND OF MY MADNESS. (My	John J. Howard	Taken to poetry as a weapon to do BATTLE against my RARE
Battle Against Huntington's Disease!)		DISEASE enemy, Huntington's Disease!. My journey began as a effort to raise awareness for H-D, which is an INCURABLE fatal genetic brain disorderover time a slow gradual killer. (Very often described as a combo of ALS, Parkinson, & Alzheimer's) Many of my family members have passed due to H-D, including my Mother, Sister, my brother currently requires on wheelchair, I also am H-D positive. A H-D family can be pretty difficult experience, but I decided it was time TO TAKE THE POWER BACK! I have written over 150 poems over the last 5 years or so, more or less documenting my emotions within that time period of my own growth, and also sharing those poems with my H-D community who has responded amazingly. They have cried the same tears I have cried, so I also continue to remain active for them.
Portraits of Huntington's	Carmen Leal	Portraits of Huntington's is a joyful collection of profiles, essays, and quotes for and about those with Huntington's Disease. Portraits of Huntington's features award winning artist Ruth Hargrave's incredible portraits of eight individuals or family groups who are all in some way touched by this genetic disease. Joy is a choice. Happiness is based on a set of circumstances, and Portraits of Huntington's asks us to choose joy. As with Faces of Huntington's, in each chapter is thematic, Knowledge, Laughter, Patience, Compassion, Faith, Love, Hope, and Joy. Whether you are a person with Huntington's Disease, a caregiver, someone at-risk, a family member, a professional, or someone who simply cares, we all need joy in our lives. Somehow, despite the horror of Huntington's Disease, remarkable heroes are choosing joy every day. I hope their inspiring lives, coupled with my stories and Ruth's portraits, will encourage you to choose joy.



		nttps://nealtn.ucdavis.edu/nuntingtons/
Title	Author/Director	Overview
Rules for 50/50 Chances	Kate McGovern	Seventeen-year-old Rose Levenson has a decision to make: Does she want to know how she's going to die? Because when Rose turns eighteen, she can take the test that tells her if she carries the genetic mutation for Huntington's disease, the degenerative condition that is slowly killing her mother. With a fifty-fifty shot at inheriting her family's genetic curse, Rose is skeptical about pursuing anything that presumes she'll live to be a healthy adult-including her dream career in ballet and the possibility of falling in love. But when she meets a boy from a similarly flawed genetic pool and gets an audition for a dance scholarship across the country, Rose begins to question her carefully laid rules.
Saint Vitus' Dance	Jill Rubalcaba	Thirteen-year-old Melanie feels angry and guilty because she is worried about herself instead of her mother, who has Huntington's chorea, a hereditary condition, until Melanie finds the strength to face her mother's illness and her own uncertain future.
Shattered DreamsBut Hope: Encouragement for Caregivers of Huntington's Disease and Other Progressive Illnesses	Laquita Higgs and Elton Higgs	Shattered DreamsBut Hope by Drs. Laquita and Elton Higgs, is a book of both testimony and advice: testimony born out of the school of trial and suffering, and advice born out of practical experience in being long-term caregivers. Laquita and Elton have for the last 26 years been caregivers to two adopted daughters with early onset Huntington's Disease (HD), which is hereditary, and they offer a gripping account of their extended experience in adjusting to the challenges of long-term caregiving, followed by sober practical counsel to others who are involved in similar caregiving experiences. A final chapter speaks specifically of the role of Christian faith in coping with the stresses of their long struggle. In the Appendices are a short talk given after Cynthia's funeral by her older sister Liann and several poems by Elton on the emotional impact of his and Laquita's relationship with their disabled daughters.
Someone Else's Life	Katie Dale	How can you face your future when your past it a lie? When Rosie Kenning's mother, Trudie, dies from Huntingdon's disease, her whole world falls apart. Not only does Rosie desperately miss her mum, but now she has to face the fact that she could have inherited the fatal illness herself. Until she discovers that Trudie wasn't her biological mother at allRosie is stunned. Can this be true? Is she grieving for a mother who wasn't even hers to lose? And if Trudie wasn't her mother, who is? But as Rosie delves into her past to discover who she really is, she is faced with a heart-breaking dilemma - to continue living a lie, or to reveal a truth that will shatter the lives of everyone around her
The Lions Mouth Opens	Lucy Walker	Follow a courageous filmmaker/actress as she prepares to learn if she has inherited the incurable brain disorder, HD.



		https://health.ucdavis.edu/huntingtons/
Title	Author/Director	Overview
The Longest Journey	Nathan Appfel	This 'beautiful and bold' film follows a blue collar family cycling 3,000 miles, 24 hours a day from coast to coast in the Race Across America to raise awareness for a terminal illness the mother is battling. Will they succeed in one of the most grueling races in the world, or will they succumb to the brutal elements? You'll walk away ready to share this film with friends and family.
The Warriors - Fighting the	Help4HD	Documentary following several families caring for youth with
Incurable Juvenile Huntington's Disease		Juvenile HD.
The Woman Who Walked	Alice Wexler	This title presents a groundbreaking medical and social history
Into the Sea		of a devastating hereditary neurological disorder once demonized as 'the witchcraft disease'. When Phebe Hedges, a woman in East Hampton, New York, walked into the sea in 1806, she made visible the historical experience of a family affected by the dreaded disorder of movement, mind and mood her neighbours called St. Vitus' dance. Doctors later spoke of Huntington's chorea, and today it is known as Huntington's disease. This book is the first history of Huntington's in America. Starting with the life of Phebe Hedges, Alice Wexler uses Huntington's as a lens to explore the changing meanings of heredity, disability, stigma, and medical knowledge among ordinary people as well as scientists and physicians. She addresses these themes through three overlapping stories: the lives of a nineteenth-century family once said to 'belong to the disease'; the emergence of Huntington's chorea as a clinical entity; and the early-twentieth-century transformation of this disorder into a cautionary eugenics tale. In our own era of expanding genetic technologies, this history offers insights into the social contexts of medical and scientific knowledge, as well as the legacy of eugenics in shaping both the knowledge and the lived experience of this disease.
a Twitch	Kristen Powers	This documentary will follow Kristen Powers as she discovers whether she has inherited the same disease that killed her mother. It will also raise awareness about Huntington's Disease to help reduce the stigma that surrounds this brain disease that affects speech, mobility and thinking. By sparking a national conversation about this disease, we can hopefully make this generation the last one with the disease through education, participation in clinical trials, and research funds. Finding a cure could potentially unlock the mysteries to other neurological illnesses such as Parkinson's, Alzheimers, ALS and various forms of dementia.
Walking the Tightrope	Randi Jones, PhD.	An in-depth examination of issues and problem common to people at risk for HD. Offering practical guidance and professional insights, this book includes sections on relationships, coping, predictive testing, resources, planning ahead, and life after a positive test result.



Title	Author/Director	Overview
Title Watching Their Dance: Three Sisters, a Genetic Disease and Marrying into a Family At Risk for Huntington's	Author/Director Therese Marin- Cutcher	Huntington's disease, considered the cruelest disease on our planet is the Marin family secret that the three sisters, Lora, Marcia and Cindy, discover when they visit an aunt they have not seen in years. The story begins with John Marin, their brother, and Therese Crutcher, his fiancé, learning of the news that the siblings have a 50/50 chance of inheriting the disease which has no therapy or cure. The news shakes Therese to her core, and she questions her engagement to John. After much soul searching, Therese takes the biggest gamble of her life and marries the love of her life knowing the possible consequences of her decision; at least two of the Marin siblings will fall prey to the disease and one of them could be John. The book chronicles the life of John and Therese, over thirty years, as they journey through life shrouded in the uncertainty of Huntington's disease. The story explores how living at risk for Huntington's impacts their life on a daily basis, how Huntington's is a factor in every important decision, how it impacts relationships, and addresses the coping skills Therese uses to manage and survive unimaginable stress and anxiety. Their lives were filled with unpredictability and pain, and yet full of love, good times, and great joy. Therese discovers acknowledging that her world could change overnight has made her life much richer. She learns to overlook shortcomings and to compromise, to let go of anger, to find joy in the simple things. The Marin siblings taught her—and can teach readers—
We Exist	Tanita Allen	about embracing life, forgiveness, and unconditional love. This story is not only about hardship. It's a narrative of strength and tenacity, a powerful testament to determination and faith in the face of systemic neglect and personal adversity. We Exist is a beacon of empowerment, offering guidance and advice to individuals navigating their own seemingly insurmountable odds. It's a call to action, advocating for oneself not just in healthcare and justice but in life. Through her own resilience and refusal to succumb to fate, Tanita Allen demonstrates the possibility of a fulfilling life despite overwhelming challenges, inspiring others to take charge of their destinies.
When Given Lemons	Lauren Holder	Lauren Holder is a young woman who deals daily with the struggles of Huntington's Disease, whether it is in her own personal life, a member of her family, or a friend of the Huntington's Disease community. She first learned of Huntington's Disease at the age of fifteen after her grandfather was diagnosed with it. This is the story of her relationship with her grandfather and how Huntington's Disease played such a huge role in it, taking their relationship from almost nonexistent to something special, a bond that changed her life.



https://health.ucdavis.edu/huntingtons/

Title	Author/Director	Overview
You'll Miss Me When I'm	Rachel Lynn	Eighteen-year-old twins Adina and Tovah have little in common
Gone	Solomon	besides their ambitious nature. Viola prodigy Adina yearns to
Gone		become a soloist—and to convince her music teacher he wants
		her the way she wants him. Overachiever Tovah awaits her
		acceptance to Johns Hopkins, the first step on her path toward
		med school and a career as a surgeon. But one thing could
		wreck their carefully planned futures: a genetic test for
		Huntington's, a rare degenerative disease that slowly steals
		control of the body and mind. It's turned their Israeli mother
		into a near stranger and fractured the sisters' own bond in
		ways they'll never admit. While Tovah finds comfort in their
		Jewish religion, Adina rebels against its rules. When the results
		come in, one twin tests negative for Huntington's. The other
		tests positive. These opposite outcomes push them farther
		apart as they wrestle with guilt, betrayal, and the unexpected
		thrill of first love. How can they repair their relationship, and is
		it even worth saving? From debut author Rachel Lynn Solomon
		comes a luminous, heartbreaking tale of life, death, and the
		fragile bond between sisters.

Finding other books/movies:

HDSA.org/publications Help4HD/resources

HDYO at <u>en.hdyo.org/you/books</u> Internet search for HD books & movies





There's an App for that!

Lisa Mooney, LCSW HD Community

This list of applications (apps) was collected from the HD community and some internet research (see references). Apps can be a great tool to assist in many areas of life. Specific to HD, I gathered some apps that may be helpful in addressing symptoms, challenges or struggles when living with HD. As with any recommendations please consult the privacy policies before sharing personal information. This list is NOT exhaustive and being on this list does not mean it is endorsed by UC Davis Health, HDSA Center of Excellence @ UC Davis or individual staff. Many apps will have FREE or Lite versions that can be used, however, to use the entire features of the app, there may be a one time, monthly or membership fee. Please review each app prior to purchase to ensure that it will meet your specific needs.



HD Information/Education:

These applications can be used to connect with HD information, education, events, and HD resources that you may benefit from.



You Tube

Huntington's Disease
Society of America &
Help 4 HD have
YouTube channels that
contain educational
videos on a variety of
HD related topics.



Social Media:

Facebook, Twitter, TikTok, Instagram (HDSA, Help4HD, HelpCureHD, etc.)



Podcasts - Live with Help4HD, HDSA, HD Insights



Smart Device Applications "Apps"

Apps to assist with Mood, Behavior, Stress and Sleep

There is an array of apps that are designed to supplement and support your mental health journey and coping. The following apps offer a variety of strategies, techniques and/or ways to track mood or behavior symptoms. If you are having mood changes or symptoms that are challenging to manage or cope with, please CONSULT with your HD team or Primary Care Physician to discuss appropriate treatment. APPS may be an additional way to cope, however should not be used in lieu of medical care or treatment and often APPS are most effective when used in COLLABORATION with therapy, medication, or other medical intervention.



What Mental Health Apps can offer

Assistance to find a therapist

Accessability &
Convinence
(assistance at your
finger tips)

privacy and anonimity

Daily reminders for coping, self monitoring

Information & Education about mental health

Coping Strategy recommendations & strategies

Helps one better understand your moods

Cost associated with premium option to

and emotions

get more accessibility

Bearable Calm	Data entered is shareable with medical professionals as you would like. Offers mood tracking, track medications, sleep, exercise, food intake, and social interactions in the app.	 Can integrate with Apple Health Kit Backed by scientific review Journal, Tracks sleep, medication, exercise, and food among other things Android users can't track data as efficiently as iPhone users App offers more individual exercises
Caim	Exercises that help manage anxiety, stress as well as offer sleep stories, guided meditations, and tools to help you improve sleep and mental/emotional health.	 App offers more individual exercises Less structured Calming sounds in background Simple to follow Need a subscription – those insured with Kaiser can get Calm free @ https://healthy.kaiserpermanente.org/health-wellness/mental-health/tools-resources/digital
Depression CBT Self-Help Guide	Cognitive Behavioral Therapy (CBT)-based guides, exercises, and tools to help you manage your depression symptoms. Teaches simple activities that are easy-to-do. Offers feedback on symptom severity. Offers relaxation audio to learn deep relaxation and diary to learn how to challenge stressful thinking.	 Contains lots of mental health information FREE access to all content and activities Android devices A screening test to monitor the severity of depressed mood Articles about clinical depression and cognitive behavioral therapy (CBT)
Happify	Science-backed games that help reduce stress, build resilience, and overcome negative thoughts.	 Free version offers limited options Developed by experts including therapists and coaches

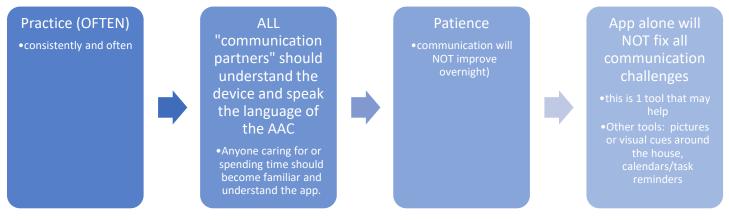
		https://meaith.acaavis.eaa/hantingtons/
Headspace Insight Timer	Teach how to meditate. Offers programs that can help manage depression, anxiety, chronic pain, etc. Learn to meditate to help calm the mind, reduce anxiety, manage stress, sleep deeply, and improve happiness. Guided meditations and talks led by the world's top mindfulness experts, neuroscientists, psychologists and meditation teachers from Stanford, Harvard, Dartmouth and the University of Oxford.	 Free to download; monthly cost to use. iOS and Android Guided meditations, sleep sounds, wind-down exercises, yoga, relaxing playlists Free Paid versions opens more features iOS and Android Can set goal or area to focus on.
Moodfit	Track moods and offers exercises to help address negative emotions. Questionnaire that will help you determine the severity of the symptoms, as well as many articles and audio files that can help you better understand what you are experiencing.	 Adaptable based on your goals Ability to track daily progress Visual insights with actionable exercises Daily reminders to keep you on track Some advanced features have additional costs
MoodMission	Research-backed and gives missions to help improve your mood and mental health skills. Meant to help people who are dealing with stress, anxiety, or depression.	 Developed by mental health professionals In-app rewards to increase motivation Mood-boosting activities Evidence-based CBT activities for depression and anxiety
myStrength	Personalized program that helps you improve your awareness and change behaviors with mindfulness and meditation activities. Tailored programs for managing depression, stress, anxiety, etc	 FREE for Kaiser Insurance persons @ https://healthy.kaiserpermanente.org/he alth-wellness/mental-health/tools- resources/digital Tools for setting & tracking goals, current emotional states and ongoing life events, and viewing your progress
Sanvello	Cognitive behavioral therapy tools to help treat mild to moderate anxiety and depression. They teach mindfulness skills and provide mood and health tracking tools that can be used to improve mental and physical health. Community that allows you to connect with another anonymously. Share advice, ask questions, or talk to others who understand what you're going through.	 Effectiveness backed by research Costs may be covered by health insurance Provides different options Ability to access a licensed therapist when you need more support May NOT be appropriate for severe mental health conditions Requires a monthly subscription to access advanced features Cost for add-on features Therapy option is not available in all states
Shine	Developed to empower Black, Indigenous, and people of color (BiPOC) by offering community support and tools that address BIPOC-specific mental health issues. Female-focused, self-care app that aims to help users "rest, heal and grow through difficulty." Offers an inclusive	 Empowering tools and activities for self-improvement Topics focused on BIPOC mental health Calming tools for crisis moments Activities based on empirical research NOT designed for more serious mental health conditions

		itteps://iteattii.acaavis.caa/itaittiigtoiis
	community so you can connect with other members at any time.	 No access to professional support Requires purchase to access many premium features Science-backed information & strategies
Talkspace	Connects you with a licensed mental health professional so you can receive therapy from your digital devices (computer, tablet, or smartphone).	 Ability to talk to a licensed mental health professional Range of price options Multiple ways to communicate with your therapist Conversations are private and secure Not appropriate for severe mental health issues
Virtual Hope Box	Developed by Nigel Bush, a research psychologist for the Defense Department's National Center for Telehealth & Technology (T2), a component center of the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury. Is a smartphone tool for moments of crisis and is intended to supplement treatments already happening. The purpose is to help patients decrease subjective experience of distress by facilitating adaptive coping and emotion regulation skills.	 Free on iOS and Android Distract Me Section: activity planner and puzzles/word search games taken from user content. Inspire Me Section: preloaded inspirational quotes, which can be supplemented or replaced by personal quotes, family aphorisms, biblical phrases, etc. Users can set a daily reminder to receive daily inspirational quotes if desired. Relax Me Section: relaxation exercises to help calm, including a deep breathing tool, progressive muscle relaxation, etc. Coping Tools Section: Collection of "coping cards" in which the patient has written down positive, realistic and adaptive thoughts and behaviors to use when in crisis or to manage problematic core beliefs.

Apps for Improved or Assistive Communication

Often referred to as Augmented and Alternative Communication (AAC) apps can be used to assist persons that have difficulty with speech or expressing themselves. These apps can be helpful for family members, caregivers, or medical providers to enhance communication and understanding of those with speech challenges. AAC apps assist individuals in forming phrases and sentences using symbols and predictive keyboards to communicate with others. This is not an exhaustive list and was put together not as an endorsement but as a resource for HD families to know what type of tools may be available to help with communication challenges.

Keys to using Communication Apps successfully



AutisMate	Allows the creation and tagging of real-world	 iPad only
	"Scenes." Users can take pictures of	 Cost to use
	surrounding environments and tag "hotspots,"	
	which, when pressed, open a menu containing	
	common phrases associated with the area.	
	Users can even create "visual schedules"	
	comprised of images representing daily tasks	
	and routines, shown in chronological steps.	
CBoard	Web app for children and adults with speech	Use with Android
	and language impairments, aiding	
	communication with symbols and text-to-	
	speech.	
iCommunicate	Visual and text as well as task completion and	 Allows you to create pictures, flashcards,
for iPad	audiovisual prompting. Large database to	storyboards, routines, visual schedules, and
	choose words and actions from, making speech	record custom audio in any language.
	available for every occasion. You can also	 Comes preloaded with 10,000 Symblstix
	record your own custom language to help	pictures.
	improve communication across language	 Can insert Google images, printable
	barriers. Allows the user to print out their	storyboards.
	schedule they have made, making this	333.7.333.333.
	application very diverse.	
LetMeTalk (iOS,	Supports communication in all areas of life.	• Free
Android)	Enables you to line up images in a meaningful	

Lil Requester (iOS)	way to read this row of images as a sentence. The image database of LetMeTalk contains more than 9,000 easy to understand images. Additionally, you can add existing images from the device or take new photos with the built-in camera. Founded by parents for parents and created to help children with socio-communication	 Supports several languages including English, Spanish, French, Italian, German, Chinese, Portuguese, Brazilian Portuguese, Dutch, and Arabic. Synthesized Speech (Computer Generated) Allows for switching back and forth between languages for families who are bilingual. Fully customizable and includes a range of communication topics such as places,
	challenges express themselves and their needs effectively. Enable the user to communicate their needs and express themselves verbally enabling them to make decisions or choices easily.	people, emotions, activities and more.
Proloquo2Go	Allows talk using symbols or text in a natural-sounding text-to-speech. This AAC can be customized to the needs of each person	 Access to 14,000 symbols and easily add your own photos. Pre-programmed vocabulary sets (Research-based: core word and basic communication) which is fully customizable. Share text in message window via email, Facebook, Twitter, and text message, or even copy and paste into other applications.
QuickTalk AAC	Comprehensive AAC application designed by educators, therapists, engineers, and parents to help individuals who are non-verbal to communicate through images, profiles, and symbols.	 Easy to navigate, quick access to Yes/No, 11,000 Symblstix images. Easy setup, create profile and start using within minutes. Add buttons before new event or on the go. Navigate to speech buttons in 1-2 clicks. High quality text to speech or use your own voice. Typing mode.
SonoFlex	Turns symbols into clear speech. It offers language to nonverbal users. The Lite version differs from the paid version in that there is a limit on the preprogrammed contexts available and reduced customization settings.	 A LITE version is available to try the app out. Core vocabulary set provided, with some context/topic-based boards also included. High-quality text-to-speech voices (US English). Fully customizable buttons, grids, and folders.
TouchChat	Symbol and text based AAC tool available for both iPhone/iPod Touch and iPad. Access to SymbolStix library, and easily add your own photos.	 Free, Lite version Pre-programmed, fully customizable vocabulary sets are available. High-quality text-to-speech voices. Share text in message window via email, Facebook, Twitter, Tumblr and text message or even copy and paste into other applications.

Physical Health, Exercise & Nutrition

Physical health, exercise and nutrition is important for ALL of US. These apps can have benefits for HD persons, care providers and family members. There are LOTS of apps available, this is only a few, please consult your medical providers before starting a new exercise program or nutrition program.

BENEFITS

Accessability & Convinence (assistance at your finger tips)

Tracking Progress towards Health Goals

May offer motivation

Information & Education about health

May be more cost effective than gyms or other options.

Apple Health (iOS)	Manage aspects of physical health, monitor sleep patterns, heart rate, count steps and track exercise via apple phone or apple device.	 Require apple device to use Come pre-loaded on most apple handheld devices or wearable devices.
FitBit (wearable devices/App)	Manage aspects of physical health, monitor sleep patterns, heart rate, count steps, track exercise and monitor nutrition.	 Wearable devices range in cost. App has FREE version and Premium paid version that unlocks more health details, nutritional information, and exercise videos. Can be linked to share data with other health applications
FITON	Offers a variety of workouts, including cardio, strength, high-intensity interval training (HIIT), dance, yoga, Pilates, Barre and more. Classes are available in real time with the app's live classes feature or through on-demand workouts.	 FREE version Pro version has annual cost. Recipes, live workout video calls, personalized meal plans
Fooducate	First launched in 2010, it's known for its barcode scanner (each item scanned is given a letter grade to help you determine if it belongs in your cart or back on the shelf when your grocery shopping) and its complete nutrition breakdowns. Help to make sure that the food and drinks you're consuming give your body what it needs. Section for healthy recipes and community support if you need fresh dinner ideas or a confidence boost.	 Free to download a Cost for some aspects or "add-ons" iOS and Android Food education, food tracker, barcode scanner, community-based support, recipes, and diet tips Daily nutrient counts

Garmin Watch/Fitness	Similar features to other fitness devices/trackers. Exclusive to Garmin is "Body Battery" (other watches have similar) but shows your "energy" as a simple line graph then will show how much energy you expend with work or fitness throughout the day.	•	Cost for wearable device
MyFitnessPal	All-in-one nutrition and fitness tracker. Provided nutritional information for over 14 million foods and a built-in fitness community to help you stay motivated. Allows users to scan barcodes for nutritional information, save meals and recipes, and use a food diary to help track eating habits over time.	•	Free to download and use Has a upgraded version for subscription iOS and Android Track calories and fitness activities, connect with friends, log food and exercise, over 350 workouts, connects to 50+ apps and devices
Nike Training Club	Access multi-week training programs catered to your specific fitness goals, as well as more than 100 standalone workout videos. Quiz asks what kind of workouts interest you most and how many times a week you want to exercise. Based on your answers, it recommends a few four- to eight-week structured programs consisting of 10-to 60-minute workouts. Nike Training Club's workout offering runs the gamut, from yoga to bodyweight boot camps to core training.	•	Free In app purchases for upgraded content.
The Daily	Offers sessions for men and women from five to	•	Free
Workouts Fitness Trainer	30 minutes. Developed by a certified personal trainer who guides you through randomized workouts crafted from more than 95 of the best moves to get your body in gear.	•	iOS and Android Exercise videos, 5- to 30-minute workouts, routines, full-body, arm, abs, and cardio sessions, and on-screen instructions and timer
You Tube	Search and find exercise videos, adaptive exercise videos (chair yoga, pool exercise, etc.) as well as demonstrations on how to transition from car to wheelchair safely as well as recommended use for mobility or adaptive equipment.	•	App is FREE Most content is free Can find information on Exercise, how to use equipment, Swallowing Tips, Cooking, etc.

Caregiving

Caregiver apps may help with organizing, problem solving, managing responsibilities, etc. These apps can assist with many aspects of caregiving from tracking symptoms of your loved one, medication tracking, organizing responsibilities, shopping, and self-care.

Organization, Sharing Information with others and staying connected

AnyList	Digital shopping list. Helps keep you organized and crosses out anything you bought. Has helped us stay organized and connected.	Free version
Care Zone	Securely manage health information. Upload or manually enter advance directives, contacts, insurance and medication information, and medical files. There's a shareable calendar and a to-do section so you can share information and assign tasks to others on your care team.	 Free Available at the Apple App Store and Google Play.
Caregiving App	Sets up and runs family and community caregiving networks. It works through interactive calendars, messaging, shopping lists and medication reminders. It tracks blood pressure, blood sugar, weight and diet making this a great health aid for the at-home caregiver.	• Free
CareZone	Invite family members and friends to join as "helpers." There is a journal section for your thoughts and notes, a task list, and an option to send a recorded voice message to up to 100 recipients.	• Free
Caring Village	Store important documents in one place, create a care team, and coordinate help with food, errands, transportation, etc., as well as keep track of medications.	 secure in-app messaging and preparedness checklists. Wellness journal Free. Available at the App Store and Google Play
Independa Caregiver	Supports a range of engagement, reminder, medical information, and support-oriented functions.	• Free
Life 360	Keep in touch with your partner and receive notifications when loved ones arrive home. Track where each other is in real time.	Free version
Lotsa Helping Hands	Invite family, friends, volunteers, and care aides to help manage everything from appointments to errands and family gatherings.	 There's a section for people to leave encouraging messages for you or your loved one. Free. Available at the App Store.

The state of the s		
For Medicati	on Tracking	
Medisafe	Easy-to-use medication reminder that also provides tips, refill reminders, progress reports and discounted prescription offers. Caregivers and health care providers can also be connected to the account.	Free.Available at the App Store and Google Play.
MyMeds	Schedule medication reminders that are sent via text. When they've taken the medicine, they reply "yes." You and other family members can be added to the tracking list so you'll get a notification if they haven't taken the meds and can send them a follow-up reminder.	 Free. Available at the App Store and Google Play.
RxSaver	Coupons to help you save money on prescriptions — whether you have insurance or not. Search medications by name, find available prices from nearby pharmacies (you can set the surrounding radius you're willing to travel within), get a coupon and show it to the pharmacist when you arrive.	Free.Available at the App Store and Google Play.
Monitoring N	Medical Health	
eCare21	Remotely monitor your loved one's glucose, heart rate, sleep, physical activity and more. With 24/7 monitoring via devices such as a FitBit or smart watch, caregivers and health providers can gather information to help them be proactive, even from a distance.	 Monthly subscriptions for increased accessibility Free version available at the App Store and Google Play.
Genie MD (google play) iVisit (iOS)	Customizable app that works as a home health aide that helps manage medications, alerts to adverse drug interactions. Tracks vitals such as blood pressure, glucose levels and cholesterol. It also aids in contacting 911 and can be synced with doctors by providing free reports.	FreeHealth Profile is sharable
PainScale	Track and monitor your loved one's pain. Enter pain triggers and intensity, activity levels, medication dosages, mood, and sleep quality. Information can be compiled in a pain report.	 Information shareable with health providers. Free. Available at the App Store and Google Play.
	oping with Cognitive Impairment	
Alzheimer's & Dementia Daily Companion	Designed for Alzheimer's caregivers (but can be used for any person caring for someone with cognitive impairment). Loaded with practical tips from experts for everyday situations and challenges.	 Free. Available at the App Store and Google Play

Dementia	Expert advice on 25 of the most	Has cost to purchase app.
Caregiver	challenging dementia-related behaviors.	 Available at the app store.
Solutions	Strategies and tips to help manage high-	
	stress situations caregivers might face.	
MindMate	Providing actionable guidance for someone	• Free
	in the earlier stages of dementia,	 Available at the app store.
	MindMate combines mental stimulation,	
	physical exercises, nutrition advice,	
	recipes, and secure storage for photos and	
	memories. Each feature is designed for a	
	holistic approach to living with dementia.	
MyReef 3D	A relaxing view of 14 different types of fish	 Free with ads
Aquarium	in a reef, the interface allows users to	 Cost to enjoy without adds
	interact with the fish or simply watch them	 Available at the app store and Google
	swim by. Great for people living with	Play.
	dementia.	

Caregiver Self-Care (see Mental/Emotional Health apps as well)

A Podcast	Download to hear discussions and advice on
Арр	everything related to caregiving. There are a
	number of podcasts that will give you
	practical advice on caregiving and self-care,
	encouragement – and the knowledge that
	you're not alone.

Examples include:

- Caregiver/Storyteller (iTunes, Google Play, Spotify)
- Caregiver Podcast (iTunes, Google Play)
- Happy, Healthy Caregiver (iTunes)
- Eldercare Illuminated (iTunes)

Any of the Apps listed in the previous sections.

Looking for MORE?

New apps are always being created and developed, if you are looking for something more or different than what is listed here, you can do a search on either your app store on your phone/tablet or internet search to find other apps of interest and benefit.

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Navigating Huntington's Disease

2025

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 916-938-3576 or 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 your feelings with somebody (partner if you can or other supportive person) 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 you 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 selfcare (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 loved 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 valuable 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 paid through insurance, privately or through employee assistance programs through your employer.
- Caregiver Education or Online Recommendations:
 - o AARP: written resources and recommendations to help caregivers under AARP Caregiving.
 - o <u>California Caregiver Resource Centers:</u> 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 of 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 useful 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 \$25-\$35 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 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 \$25-\$35 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 Click "Subscribe" banner at the bottom of the webpage and enter your contact information.
- Northern California HDSA Chapter: http://northernca.hdsa.org/ Scroll near bottom of page to the area titled Newsletter Sign Up, use the "click here to sign up " and enter your information.

Where can I get more education about HD?

Local Education Events

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, webpages or webinar:

Website: https://health.ucdavis.edu/huntingtons/

Facebook: https://www.facebook.com/UCDavisHuntingtons AND

https://www.facebook.com/hdsanocal/

YouTube: https://www.youtube.com/@hdsaspacificwestregion1677 AND

https://www.youtube.com/@help4hdtv

What support is available in Northern California for HD families?

Northern California is an area rich in HD support. We have 4 HDSA Center of Excellence's, 3 local support groups per month primarily video, 3-5 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 @:

- Northern California HDSA Chapter: http://northernca.hdsa.org/ Scroll near bottom of page to the area titled Newsletter Sign Up, use the "click here to sign up " and enter your information.
- You may also check the webpages and Facebook pages listed in the previous question.
- Support Groups: please visit the HDSA Center of Excellence @ UC Davis,
 Northern California HDSA Chapter, HDSA Bay Area Affiliate for local support groups. All groups are available for register at www.heypeers.com

My HD loved one is living in another state, how can I support them?

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 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 variety of services including:

- <u>Supportive Counseling for HD patients, families and caregivers</u>: family care meetings, grief support, presentations/trainings about HD, problem solving, emotional support.
- <u>Information about Community Resources and Benefits:</u> Medi-Cal, Disability, in home assistance, Out of Home placement, Adult Day Health Care, HD support groups, etc.
- <u>Information and Education about HD:</u> 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 916-938-3576 or lkier@hdsa.org. Each of the other 3 local HDSA Centers of Excellence also have HD Social Workers as well.

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:

- <u>Social Security Disability Forms:</u> 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.
- <u>Financial Power of Attorney</u>: 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 916-938-3576 to discuss your specific needs.

Financial Resources

I heard social security added HD as a disability, what does that mean?

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 www.ssa.gov. For information about tips and recommendations for applying for disability under HD diagnosis, please visit: the UC Davis HDSA Center of Excellence Website – How to Apply for Social Security Benefits or HDSA.org for more disability information.

When should I apply for Disability?

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 State Disability at:

https://www.edd.ca.gov/Disability/Disability Insurance.htm
State Disability is considered short term disability and will only cover up to 12 months of your disability.

Social Security Disability – 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 www.ssa.gov 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.

Do you know of any outside funding sources if our family is not able to meet our obligations?

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.

We are having difficulties paying our mortgage, there are some programs that adjust mortgages due to hardship; are there any negatives in doing this?

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 up-to-date information/programs available as well as pros/cons.

Future Planning

How does long term care insurance work?

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.

When should I get long term care insurance, life insurance, disability insurance?

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.

When should we complete an Advance Health Care Directive, Living Will or Durable Power of Attorney?

Completing Advance Health Care Directive, Living Will, or Durable Power of Attorney should be *DONE for all persons* (not just those with HD) as soon as possible. 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

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?

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, HDSA.org, or Coalition for Compassionate Care of California.

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:

- Set realistic expectations 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.
- Why do you want to share or discuss with your HD loved one? 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.
- 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 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 (Kaiser and UC Davis) 10 minutes gives overview, things to consider, etc. https://kp.qumucloud.com/view/nxFlJOisZoi
- 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 through medical insurance, private pay or employee assistance programs through your or your spouse's employer.

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 system to get all our needs met.

Tips how to safely transfer to/from car in late stages of disease?

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.

If you plan to stay in a private home, consider exploring options for equipment or

Home Safety, Accessibility and Modifications

Bathing:

home modification like:

(additional tips/recommendations in the Medical Assessment, Equipment and Modifications section in this document)

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.

 If bathroom cannot accommodate the needs of a disabled person, you may consider remodeling the 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.

• Rest of Home:

o 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, hover lift, etc. and other persons to safely been in room to assist with transfers and care needs.

For assistance with identifying way to modify your home to accommodate someone with HD or other disabilities we recommend:

- Research and talk with professionals about things to consider as disease progresses.
- 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
- Please follow these links for some helpful resources about home modifications, home safety and things to consider:
 - O AARP:
 - Rebuilding Together:
 - Eldercare Locator

How do we navigate the HD progression? Are there resources/tips to make life easier for HD person and Caregiver?

There is not necessarily and right or wrong way to navigate HD progression, as it is different for everyone. Some recommendations include:

- Seek HD specialized care for assistance with treating current symptoms and planning for what may come next. See Community Resources for HD section of this document for a list of HDSA Centers of Excellence in 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
- o 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.
 - o 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.

<u>Assisted Living Facilities</u> 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 \$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 contact your nearest HD social worker.

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 <u>VA Nursing Home</u> 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 <u>www.va.gov</u>.

There are also <u>Veteran Homes in California</u>. 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 <u>www.cdva.ca.gov</u>.

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 support groups www.heypeers.com

• Individual Therapy/Counseling – paid through insurance, privately or through employee assistance programs through your or your spouse's employer.

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

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:

- <u>HD Support Groups</u> are a valuable 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

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.)?

- 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 my 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?

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

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 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 nik-naks, 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
- www.hdtrials.org
- www.huntington-study-group.org
- www.clinicaltrials.gov
- 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) 734-7706

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 are 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

	1 7
	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 facilitated or monitored, so please use caution when seeking advice or recommendations and always discuss issues/concerns with your medical team as well.
	HD Support for Youth & Young Adults
	 Huntington's Disease Youth Organization (HDYO) is a great resource 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.
	Support Groups (Non-HD specific)
	 Caregiver Support: these are individuals caring for an aging or disabled adult. California Caregivers Resource Centers
	 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.
	 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.
I am retiring from work	To increase and/or maintain social interaction you may want to consider:
and will miss the social	 Volunteering for a cause that is of interest to you.
interaction, what	Participating in an HD support group.
resources can you recommend?	 Plan and schedule frequent gatherings with friends/family/neighbors/co- workers.
	 Local senior centers offer a variety of activities, gatherings for persons 65 years or older.
	Join a local church group.

• Many local coffee shops, libraries, community centers will have postings of

the social activities/events happening in the community.

Who/Where can I go for moral support when family members are not supportive or just don't understand my perspective or grief? 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, 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 grief.

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 educational events, HD advocacy events and HD support groups. For everybody:

- Northern California support groups
- Individual therapy/counseling paid through insurance, privately or through employee assistance programs through your or your spouse's employer.
- Talk to your HDSA Center of Excellence or Chapter Social Worker or HD Clinic Coordinator:
 - Lisa Mooney, Chapter Social Worker 916-938-3576 or lkjer@hdsa.org

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

• HDSA Video Support Groups

If you have any questions, concerns, or need additional assistance, please contact Lisa Mooney, Social Worker, at 916-938-3576 or lkjer@hdsa.org. Additionally, if you notice any errors or outdated information, please let us know so we can correct and update it as needed.