

HUNTINGTON'S DISEASE (HD)

CAREGIVING CHALLENGES

Often, many families find the positive diagnosis of Huntington's disease (HD) to be devastating. Even with known family history, a new diagnosis can still be a challenge for the adoption of successful coping strategies. Because HD is a fatal disease for which there is currently no cure, one adversity may be acceptance of the diagnosis. Another significant challenge for caregivers is finding the time and energy to take care of themselves. Therefore, it is important to attend support groups, talk with friends, get exercise and plenty of sleep, and participate in other activities to help maintain a balance. Likewise, it is important to acknowledge one's emotions. Feeling tired, isolated, helpless angry or scared can all be indications that the caregiver is trying to do too much and may suffer burnout. A great benefit may be to accept help from others and to ask for help when needed, especially with tasks such as grocery shopping, running errands, and picking up prescriptions. All of these things will allow the caregiver to provide better care for their loved one.

STRATEGIES FOR COPING

One strategy for coping is through education. Family counseling may help by providing an opportunity to ask questions regarding how the gene is transmitted, when disease onset might occur, what are typical symptoms and what to expect as the disease progresses. Treatment usually focuses on alleviating the psychiatric and motor symptoms. Depression can occur in HD and it is important for the caregiver to be attentive to changes in the person's mood. Medication can be prescribed to reduce feelings of worthlessness. The hallmark sign of HD is chorea, the unique movements of twisting or jerking. In most circumstances, these movements do not appear to disturb the patient. But they can be very upsetting for loved ones to watch. If chorea interferes with patient care or quality of life, or is bothersome to a patient, a physician may be able to prescribe medications that may help alleviate these symptoms. At the end-stage of the illness, close collaboration with a physician or other health care provider is essential to optimize the management of symptoms. Hospice organizations can be very helpful in the management of symptoms and arrangement of in-home care. Depending on the severity of end-stage symptoms, it may be necessary to consider nursing home placement. Visiting nurses, home health aids, volunteer services and other community resources may likewise be helpful in providing the monitoring and assistance that goes beyond what a family can manage on their own.

SAFETY AND ENVIRONMENT

Providing a safe environment to prevent injury and addressing aggressive or agitated behavior is an imperative for the family taking care of someone with HD.

Due to the debilitating nature of the disease, caring for a patient with HD can be physically and emotionally exhausting. As the disease progresses and patients become unable to perform activities of daily living (ADLs), they require increased amounts of care. A person with HD eventually becomes dependent for all basic needs (eating, toileting, and bathing). Most likely, adaptive equipment will be necessary to help care for your loved one. Your local physician can help you by ordering a home safety evaluation by an occupational therapist (OT). Maintaining balance is a common problem and can result in increased falls. An evaluation by a physical therapist (PT) can sometimes be helpful as well, particularly in the early stages of the disease when patients have more mobility of limbs. The OT and PT will determine what adaptive equipment may be helpful.

For example, a grab bar in the shower may facilitate safe bathing. Weight loss, not due to decreased caloric intake, is a common feature of patients with HD. In later stages of the disease, patients are often bed-bound and have significant swallowing problems. Special devices to assist in ADLs, special diet to aid in swallowing, and increasing calories to counteract weight loss may eventually require consideration.

In some cases, the patient may not recognize that their behaviors or personality traits are changing. It is important to remember that the patient may not have control over some behaviors and not blame the patient. Behavior modification may be helpful for minimizing unacceptable or dangerous behaviors. Behavior modification consists of rewarding appropriate or positive behaviors and ignoring inappropriate behaviors (within the bounds of safety). Reality orientation, with repeated reinforcement of environmental and other cues, may help reduce disorientation.

PLANNING FOR THE FUTURE

At the end stage of the disease, patients with HD will be bed-bound, often not speaking or moving. Most common causes of death are infection, fall-related injuries, and other complications.

Legal advice may be prudent early in the disease process to help form an advanced directive. A social worker can help you with this. An advanced directive is a legal document that outlines what type of care the affected individual would like at the end of life. As early as possible in the course of the illness, it is a good idea to think about who will be making decisions for the person with HD when they are no longer able to do so for themselves. One should consider having a Durable Power of Attorney for Health Care and/or Finances appointed while a the person is still able to make such decisions; a Durable Power of Attorney can legally make medical or financial decisions for the patient when the patient is not capable of doing so for themselves. It is important to determine what type of medical and or surgical intervention they would like in case of emergency. Talking openly amongst the family may be difficult, but it is important to ask the tough questions, especially in order to learn about and implement the patient's choices.

For the family taking care of a person with HD, there are many challenges and many questions. Below is a list of organizations that may be able to help and websites that provide additional information on HD.

If you live in the San Francisco Bay Area, we offer an **HD Support Group** for family members or caregivers.

For more information and support:

HDSA Northern California
3940 Industrial Blvd. Suite 100-D
West Sacramento , CA 95691
(916) 372-1894
(916) 371-2468 Fax
accohn@sundt.com Email

[National Institute of Neurological Disorders and Stroke](#) (NINDS)
National Institutes of Health
31 Center Drive MSC 2540
Bethesda, MD 20892-2540
(301) 496-5751 or (800) 352-9424