

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.

