What Advanced-Stage HD Looks Like

Health care professionals look at HD as a disease made up of three disorders—a movement disorder, a cognitive disorder, and an emotional disorder. Some people with HD have a very severe movement disorder but very little cognitive impairment. Others have profound cognitive changes but few movement problems. The emotional disorder is often depression, which comes and goes throughout the course of the disease. We'll look at each one of the "trio of disorders" in the following pages.

Every person experiences the beginning of HD in a unique way. Some first notice small subtle movements. Others find themselves becoming forgetful, and still others become depressed. Every person experiences the progression of HD in a unique way, too. For example, one might have a rapid deterioration in cognitive function and less decline in the control of movements. Another person may have rapidly increasing difficulty with movements, but no significant change in cognitive functioning during the same period of time. Therefore, no two people with HD will present the same caregiving challenges. But in the most advanced stages, all symptoms converge in a predictable manner.

Movement Changes

By the time a person with adult-onset HD comes to a long-term care facility, the movement disorder is usually quite apparent. But some years before, it began with small changes in eye movement and involuntary movements of the fingers and face. The symptoms progress to a point where all muscles are affected, and walking takes on a "dance-like" quality. People often try to camouflage and control the movements. As the involuntary movements, often referred to as chorea, become more exaggerated, what was once "dance-like" now looks "drunk-like". Speech becomes affected as words are slurred. As balance deteriorates, falling occurs more often, and the affected person becomes unable to walk safely without assistance. Beds may need padded side rails to prevent the patient from bruising himself or falling out.

At the same time, it becomes increasingly difficult for the person with HD to speak and be understood. Nearly all people develop a swallowing disorder, need a special diet, and need assistance eating. At some point, a decision will have to be made whether or not to insert a feeding tube. This decision involves the affected person and family members, and it is most helpful if it is made well in advance. In addition, most residents eventually need adapted beds and wheelchairs to accommodate their severe involuntary movements, impaired balance, and changes in posture.

Cognitive Changes

The cognitive disorder is less apparent than the movement disorder, but more disabling in many ways. Long before he came to you for care, he struggled with subtle changes that affected his work and family. Most likely, his ability to organize and plan his work day slowly began to erode, and routine tasks, previously performed effortlessly, became more complicated to complete. As cognitive function continued to deteriorate, he may have become quite inflexible, wanting things done a certain way. People around him may have noticed these small but significant changes in temperament. Long-term relationships may have been jeopardized. He may have been unable to see changes in himself, and vigorously denied their existence.

Now, in your care, his thinking is slower, initiating action is more difficult, learning new things is not as easy as it once was, and judgement is impaired. He may have developed difficulty waiting for things he wants immediately and become unreasonably demanding of his family, friends, and caregivers. Now these problems challenge you as you assist him in his daily activities.

Emotional Changes

The emotional disorder is primarily made up of the depression that runs throughout the course of HD. Having seen his parent suffer with HD, knowing that only further decline and dependence is at hand, and recognizing all that he's already "lost" to HD, it's easy to see why he might have a reactive depression.

Idiopathic depression, one that is not triggered by life's events, is also common. Some people with HD who are depressed appear irritable or angry. Some deny depression because they lack insight. Others are unconsciously protecting their feelings. Even in the most advanced stages of HD, people who show classic signs of depression can respond well to medication. Suicide in HD occurs more often than in the general population. Depression paired with a lack of impulse control makes suicide a major risk for patients in all stages of the disease.

In Summary...

There's no typical person with HD. Each individual has complex, unique needs. Some needs can be met easily. Others will require clever or creative solutions. And still others will require an ongoing trial-and-error approach. Taken together, though, you'll become well-versed in this person's care, and your rewarding days will far outnumber your challenging ones!

Taken from the publication A Caregiver's Handbook for Advance-Stage Huntington Disease. To see the full publication and for more resources please see the publications list on our website www.huntingtonsociety.ca