

A Compilation of the Stages of Huntington's Disease

Early - Early Intermediate Stages

Stated in positive terms from the *person's* point-of-view.

Defiance

"I'm not denying the diagnosis, I'm defying the verdict!
I'm not refusing to accept it,
I'm just boldly resisting the inevitable!"

Perseverance

"I'm continuing on...in spite of all the difficulties
This damn disease puts in front of me."

Early Stages

Early in the disease, manifestations include subtle changes in coordination, perhaps some involuntary movements, difficult thinking through problems, and often, a depressed or irritable mood.

At this stage, medications are often effective in treating depression and other emotional symptoms. It is a good time to begin planning for the future. Financial plans should be made and legal documents drawn up.

The person is diagnosed as having HD and can function fully both at home and work. In addition to the physical symptoms of HD, there are often subtle **cognitive** signs as well.

Initial stages

People with early Huntington's may find they have difficulty organizing routine matters or coping effectively with new situations. Difficulty recalling information may make them appear forgetful. Work activities may become more time-consuming, and decision-making and attention to detail may be impaired.

Early emotional symptoms may be equally subtle. Individuals at this stage may experience more periods of depression, apathy, irritability, or impulsiveness, or perhaps changes in personality.

At this stage, people with Huntington's can function quite well at work and home.

Early Intermediate Stage

The person remains employable but at a lower capacity. They are still able to manage their daily affairs despite some difficulties.

In addition to the physical symptoms of HD, there are often subtle **cognitive** signs as well.

Intermediate stages

As the disease progresses, the symptoms become worse. The initial motor symptoms will gradually develop into more obvious involuntary movements such as jerking and twitching of the head, neck, arms and legs. These movements may interfere with walking, speaking and swallowing.

People at this stage of Huntington's often look as if they're drunk: they stagger when they walk and their speech is slurred.

They have increasing difficulty working or managing a household, but can still deal with most activities of daily living.

Late Intermediate Stage

Stated in positive terms from the *person's* point-of-view.

Compassion

"I'm sorry for the trouble I'm causing my family and everyone else who cares for me. I wish I could do something to help them."

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Late Intermediate Stage

The person can no longer work and/or manage household responsibilities. They need considerable help or supervision to handle daily financial affairs. Other daily activities may be slightly difficult but usually only require minor help.

Middle Stages

In the middle stage involuntary movements (chorea) may become more pronounced. A staggering gait can sometimes be mistaken for drunkenness. Speech and swallowing will begin to be affected.

It is important to consult a speech therapist who will be able to offer suggestions and strategies for improving communication and swallowing abilities. Likewise, occupational and physical therapists can develop programs to help maintain the highest level of functioning and thereby improve quality of life.

Thinking and reasoning skills will also gradually diminish. At this stage it may become increasingly difficult to hold a job and to carry out household responsibilities.

Here again, simple strategies may be employed to help decrease frustration, increase functioning and prolong independence. For example, disorientation and short-term memory loss can be addressed by labeling drawers, maintaining a daily routine and posting a calendar appointments and events.

Advanced Stages

Stated in positive terms from the *person's* point-of-view.

Stamina

"I'm not sure just what it is but something keeps me going!
It keeps me going through all my fatigue and all the
problems and hardship this damn disease presents me."

Grace

"I've quietly resigned myself to needing others
to care for me, to sustain me. I can't show them,
but I'm more concerned for the welfare of
those around me than I am for myself.
We know we're there for each other

Early Advanced Stage

The person is no longer independent in daily activities but is still able to live at home supported by their family or professional carers.

Advanced Stage

The advanced stages of Huntington's typically involve fewer involuntary movements and experience more rigidity. People in this stage of HD can no longer manage the activities of daily living, and they usually require professional nursing care.

Difficulties with swallowing, communication and weight loss are common. Choking on food becomes a major concern, as does the weight loss. At this stage people with HD are totally dependent on others for all aspects of care, they can no longer walk, and not able to communicate their needs.

Although cognitive abilities are severely impaired, it is *important* to remember that the person is generally still aware of his/her environment, remains able to comprehend language, and remains an awareness of loved ones and others. He/she may continue to enjoy looking at photographs and hearing stories of family and friends.

People do not die from HD itself but rather from a complication of the disease, such as choking, pneumonia, heart failure or infection developing from the body's weakened condition. Death generally occurs about 15 to 20 years after onset.

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The below comments were made by two Huntington's Disease family Caregiver's. Both poignantly express the very diverse and often perplexing "symptoms" that HD may have on families.

| HD Is Like A Tornado | My P.T.A. |
|--|---|
| <p>Life is like a tornado when living with Huntington's Disease; everything gets twisted and you can have many different things blowing in the wind.</p> <p>A tornado doesn't just pick up cars; it picks up houses, children, banks, and it can flatten <i>anything</i> and <i>everything</i> in its path.</p> <p>Like HD, it can blow down one house and let the one next store stand untouched.</p> | <p>Patience - Reminding myself to be patient and remember that it takes my loved one longer to accomplish something.</p> <p>Time - Reminding myself to give my loved one lots of time to say or do things.</p> <p>Attitude - Remembering to check MY attitude. If I don't have the right attitude, then how can I accomplish my first two parts?</p> |

It is hoped that when you read the various descriptions of the "*Stages of Huntington's Disease*" that you will remember you are not alone! Either as the person with HD or the care person, remember there is a lot of support available to help you through these "stages of HD"!