WHAT IS HUNTINGTON DISEASE (HD)?

Huntington disease (HD) is an inherited brain disorder that causes changes in movement, thinking, and emotions over time. As the condition progresses, these changes can affect daily life, relationships, and independence. Families may begin to notice differences in mood, coordination, or memory that raise questions about what is happening and what to expect next. This factsheet can help individuals, families, and caregivers understand what HD is, how it develops, and why early awareness and planning can make a difference in care and quality of life.

What Does Huntington Disease Mean?

Huntington disease (HD) is a genetic brain disorder that slowly gets worse over time and affects each person differently.

Breaking down the words:

- **Genetic** – HD runs in families and can be passed from parent to child.
- **Neuro** – means it affects the brain and nervous system.
- **Degenerative** – means it gets worse gradually over time.
- **Disorder** – another word for disease or condition.

Together, these words mean HD affects brain cells and slowly changes how the body and mind work.

When HD Appears

- Symptoms usually begin between ages 35 and 55.
- If symptoms start after age 60, it's called Late-Onset HD (about 10% of cases).
- If symptoms start before age 20, it's called Juvenile HD (JHD) (about 10% of cases).
- JHD often progresses more quickly.

For more on JHD, see the Huntington Society of Canada's JHD fact sheets.

Main Symptoms of HD

Symptoms appear in three main areas, called a triad:

1. Physical (movement) symptoms

- Involuntary, dance-like movements (chorea)
- Trouble walking, talking, or swallowing
- Poor coordination
- Weight loss

2. Cognitive (thinking) symptoms

- Trouble focusing or remembering information
- Difficulty planning or making decisions
- Reduced awareness of changes in behaviour
- Word finding and communication difficulties
- Impulse control and regulating emotions challenges
- Getting 'stuck' on ideas (perseveration)

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Main Symptoms of HD Continued:

3. Psychiatric (emotional) symptoms

- Depression or sadness
- Anxiety or irritability
- Lack of interest or motivation (apathy)
- Obsessive or repetitive behaviour

Every person experiences HD differently — no two people are exactly the same.

Who Gets HD?

- HD is genetic and caused by an expanded gene that is dominant.
- A person only needs one copy of the HD gene to develop the disease.
- Each child of a parent with HD has a 50% chance of inheriting the gene.
- Both males and females are equally at risk.
- HD affects people around the world, in all cultures and regions.

STAGES OF HD

Early Stage

People can usually work and manage daily life.

They might notice:

- Trouble organizing tasks or adapting to change
- Forgetfulness or slower decision-making
- Mood swings or irritability
- Small, involuntary movements (fidgeting, twitching, restlessness)
- Changes in handwriting or driving

Middle Stage

Daily tasks become harder to manage.

People may have:

- More obvious involuntary movements (chorea)
- Problems with walking, balance, and coordination
- Slower speech and thinking
- Difficulty swallowing
- Weight loss

Advanced Stage

People need full support for daily care.

Common symptoms include:

- Less movement but more stiffness (rigidity)
- Greater swallowing problems
- Trouble speaking, though they often still understand others
- Severe weight loss
- Inability to walk
- Full dependence on caregivers

Treatment and Research

- Right now, there are no medications that stop or slow HD.
- Some drugs can help manage symptoms such as movements or mood changes.
- Ongoing research in Canada and worldwide offers hope for new treatments in the future.

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RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: contactme.cloud/form/huntingtonsociety

Informational fact sheets for family and friends impacted by HD are available to view, print and download at hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca

- A Physician's Guide to the Management of Huntington Disease
- Understanding Behaviour in Huntington Disease: A Guide for Professionals
- A Carer's Guide for Huntington Disease

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