CONDITION

Huntington disease

Huntington disease is an inherited condition that gradually affects movement, thinking, mood, and behaviour.

WHAT IT IS
Inherited condition causing progressive brain cell damage

BODY SYSTEM
Brain and nervous system

MAIN SYMPTOMS
Involuntary movements, thinking changes, mood changes, swallowing problems

WHAT CAUSES IT
Inherited HTT gene expansion

HOW IT IS DIAGNOSED
Neurological assessment and genetic blood testing

MAIN TREATMENT
Symptom medicines, rehabilitation, mental health and practical support

CAN IT BE CURED?
No, current treatments cannot stop progression

IS IT AN EMERGENCY?
Sometimes, with suicidal intent or severe choking

LONG-TERM OUTLOOK
Progressive disability with increasing support needs

Overview

Huntington disease is an inherited condition that gradually damages nerve cells in the brain. It affects movement, thinking, emotions, and behaviour. Symptoms usually begin in adulthood, although they can start earlier or later.

One well-known symptom is chorea , meaning brief, irregular movements that a person cannot control. Huntington disease was once called Huntington's chorea, but chorea is only one part of the condition.

The changes are progressive, meaning they become more significant over time. The speed and pattern of progression differ between people, including within the same family.

There is currently no cure or treatment that stops the underlying brain changes. However,

medicines, rehabilitation, mental health care, nutritional support, and practical planning can reduce symptoms and help maintain independence and quality of life.

Symptoms

Early symptoms may be subtle. A person might seem more irritable, have difficulty organising tasks, or develop small movements that initially look like restlessness. Sometimes relatives or coworkers notice changes before the affected person does.

Movement symptoms can include:

Thinking changes often affect planning and mental flexibility rather than memory alone. It may become harder to switch between tasks, make decisions, stay focused, or control impulses. Work, driving, finances, and household routines may gradually become more difficult.

Mood and behaviour symptoms can include depression, anxiety, irritability, loss of motivation, obsessive behaviour, or emotional outbursts. Some people have reduced awareness of their symptoms. Less commonly, they may develop psychosis, which can involve hallucinations or strongly held beliefs that are not based in reality.

When Huntington disease begins during childhood or adolescence, it is called juvenile Huntington disease. Stiffness, slowed movement, learning difficulties, and seizures may be more prominent than chorea.

These symptoms can have other causes. Having one or more of them does not mean that you have Huntington disease.

- Jerking, twitching, or writhing movements
- Clumsiness, poor balance, and falls
- Slower or less precise voluntary movements
- Muscle stiffness or abnormal postures
- Changes in speech, chewing, or swallowing

Causes and risk factors

Huntington disease is caused by a change in a gene called HTT . The change involves an expanded section of DNA known as a CAG repeat. This causes the body to produce an altered form of the huntingtin protein, which damages certain brain cells over time.

The condition follows an autosomal dominant inheritance pattern. This means that a person

needs to inherit one altered copy of the gene to develop the condition. Each biological child of an affected parent has a 1 in 2 chance of inheriting that altered gene.

A child who does not inherit the altered gene cannot pass it on. The condition does not skip a generation through someone who did not inherit the gene.

Larger expansions are often linked to an earlier age of onset, but a genetic test cannot accurately predict exactly when symptoms will begin or how quickly they will progress. The repeat can sometimes become larger when passed to a child, especially through the biological father.

Most people have an affected parent, but the family history may not always be clear. A parent may have died before developing noticeable symptoms, been misdiagnosed, or never undergone genetic testing.

Diagnosis

Diagnosis begins with a detailed medical and family history. A clinician usually assesses movements, balance, speech, eye movements, thinking, mood, and behaviour. Brain imaging may be used to look for changes associated with Huntington disease or to rule out other causes, but imaging alone does not confirm the condition.

A blood test that examines the CAG repeat in the HTT gene can confirm the diagnosis in someone with symptoms.

An adult with a family history but no symptoms may choose predictive testing to learn whether they inherited the altered gene. This is a major personal decision because a positive result may affect emotional health, relationships, work, insurance, and family planning. A structured testing process normally includes genetic counselling and psychological support before and after the result.

Testing children who do not have symptoms is generally avoided because Huntington disease usually begins in adulthood and there is no preventive childhood treatment. Testing may be considered when a child has symptoms suggesting juvenile Huntington disease.

Treatment and management

There is no current treatment that cures Huntington disease or reliably stops its progression. Care focuses on controlling symptoms, preserving abilities, and helping the person and family plan for changing needs.

Medicines may reduce troublesome chorea. Options include medicines that lower the activity of dopamine, a brain chemical involved in movement. Some antipsychotic medicines may help when chorea occurs alongside agitation, psychosis, or severe behavioural symptoms.

These medicines can cause effects such as sleepiness, stiffness, slowed movement, low mood, or restlessness. Treatment therefore needs regular review. Reducing visible movements is not always helpful if the movements are mild and the medicine makes walking, swallowing, or alertness worse.

Depression, anxiety, irritability, obsessive symptoms, and psychosis may be treated with appropriate mental health medicines and psychological support. Thoughts of suicide require prompt attention, particularly around diagnosis or when independence is changing.

Rehabilitation is an important part of care:

Swallowing assessments may lead to changes in food texture, mealtime positioning, or communication methods. A feeding tube may be discussed in later stages if eating becomes unsafe or does not provide enough nutrition. This is a personal decision that should consider the person's goals and previously expressed wishes.

Planning may also cover driving, employment, finances, legal arrangements, future care, and participation in research. Decisions are often easier when discussed before communication or decision-making becomes difficult.

- Physiotherapy can support strength, balance, posture, and safer movement
- Occupational therapy can adapt daily activities, work, and the home
- Speech and language therapy can help communication and swallowing
- Dietetic support can address weight loss and difficulty eating
- Mental health and social care can support behaviour, relationships, and planning

Complications

Balance problems and reduced judgement can increase the risk of falls and injuries. Swallowing problems can allow food, drink, or saliva to enter the lungs. This is called aspiration and can lead to pneumonia.

Weight loss is common and may result from increased energy needs, involuntary movement, difficulty eating, or reduced interest in food. Communication may become harder even when the person still understands what is being said.

Depression and suicide risk are important complications. Later in the condition, a person may

need help with most daily activities. Infections, choking, falls, and other effects of reduced mobility or swallowing are common causes of serious illness.

Prevention

Huntington disease cannot be prevented through diet, exercise, supplements, or other lifestyle changes. A person who inherited the altered HTT gene did not cause it through anything they did.

Genetic counselling can explain the chance of passing the gene to a child. Reproductive options may include pregnancy without genetic testing, prenatal testing, donor eggs or sperm, adoption, or in vitro fertilisation with preimplantation genetic testing. This testing checks embryos for the familial gene change before transfer to the uterus.

These choices are personal and may involve medical, emotional, financial, cultural, or ethical concerns. Genetic counselling provides information and support without deciding for you.

Living with it and what to expect

Huntington disease usually changes over many years. Early on, many people remain independent but may need adjustments at work, help with complex finances, or a review of driving safety. Regular routines and one task at a time can make thinking difficulties more manageable.

As the condition progresses, movement, judgement, communication, and swallowing usually become more affected. Chorea may become less obvious in later stages while stiffness and slowed movement increase. A reduction in jerking movements does not necessarily mean the condition is improving.

Exercise suited to the person's abilities can help maintain mobility and confidence, although it does not stop progression. A stable routine, calm communication, and a safe home layout can reduce frustration and injury risk.

Relationships may be affected by personality changes, loss of motivation, or reduced awareness of symptoms. These behaviours can come from changes in the brain rather than deliberate choices. Families and carers may benefit from counselling, respite care, support groups, and practical assistance.

Most people eventually need extensive daily support. The timing cannot be predicted precisely from a genetic result. Regular follow-up helps the care team respond as movement, mood, nutrition, communication, and support needs change.

When to get medical help

Arrange a routine medical review if you or someone close to you has gradually developing involuntary movements, changes in coordination, or persistent changes in thinking, mood, or behaviour. This is particularly important when Huntington disease is known in the family.

If you already have the condition, request a prompt review for worsening swallowing, repeated coughing during meals, unexplained weight loss, frequent falls, major behaviour changes, or possible medicine side effects.

Seek urgent medical help if someone:

Call emergency services for an immediate suicide plan or attempt, severe choking, inability to breathe, loss of consciousness, or a serious injury. Sudden weakness, facial drooping, or speech loss also needs emergency care because these can be signs of a stroke, not the usual gradual progression of Huntington disease.

- Has new or worsening thoughts of suicide or self-harm
- Is unable to eat or drink safely
- Develops fever, breathing trouble, or marked drowsiness after choking
- Becomes severely agitated, confused, or unable to stay safe

Common questions

Is Huntington disease always inherited?

Almost always. A person with Huntington disease usually inherited the altered HTT gene from a biological parent. The family history may be unknown or unclear if relatives died young, were misdiagnosed, or never had testing.

If my parent has it, will I get it?

Each biological child of an affected parent has a 1 in 2 chance of inheriting the altered gene. The outcome for one sibling does not change another sibling's chance. Only genetic testing can show whether you inherited it.

Can I have the gene without symptoms?

Yes. A person can carry the altered gene for years before symptoms begin. Predictive testing can identify the gene change, but it cannot give an exact starting age or forecast the course of the condition.

Does everyone with Huntington disease have chorea?

No. Chorea is common, but stiffness, slowed movement, thinking changes, depression, irritability, or loss of motivation may be more noticeable. Juvenile Huntington disease often causes stiffness and slowed movement rather than prominent chorea.

Can Huntington disease be cured?

There is currently no cure, and available treatments do not remove the altered gene. Medicines and supportive therapies can ease particular symptoms, protect safety, and help a person remain active and involved for as long as possible.

How long can someone live with Huntington disease?

The condition usually progresses over many years, but the course is not the same for everyone. Age at onset, swallowing safety, mobility, mental health, infections, and general health all influence long-term outlook.

Sources

- National Institute of Neurological Disorders and Stroke. Huntington's Disease . National Institutes of Health
- Caron NS, Wright GEB, Hayden MR. Huntington Disease . GeneReviews . University of Washington, Seattle
- Bachoud-Lévi AC, Ferreira J, Massart R, et al. International Guidelines for the Treatment of Huntington's Disease . Frontiers in Neurology . 2019;10:710
- NHS. Huntington's disease
- Huntington's Disease Society of America. Genetic Testing Protocol for Huntington's Disease . 2016