

Huntington Disease

A plain-English guide for you and your family

WHAT IS HAPPENING

Normally, your brain has areas that work together to control movement, memory, and emotions. One important area is called the striatum, which acts like a control center that fine-tunes your movements and helps you think clearly. In Huntington disease, a gene change causes the body to make a damaged protein called huntingtin. This abnormal protein builds up inside brain cells in the striatum and other areas, slowly killing them over many years. As these control centers break down, people develop jerky movements they cannot control, have trouble thinking and remembering, and may struggle with depression or other mood changes. Because this is an inherited condition, children of affected parents have a 50% chance of inheriting the gene change.

What you might feel

- Chorea (involuntary jerky movements)
- Difficulty walking and frequent falls
- Depression and apathy
- Difficulty swallowing (dysphagia)
- Irritability and angry outbursts
- Memory problems and slowed thinking
- Weight loss despite adequate food intake
- Suicidal thoughts or attempts

Call the doctor right away if...

- New or worsening suicidal thoughts (suicide risk is 4 to 6 times higher than general population)
- Choking episodes or recurrent pneumonia (suggests aspiration and need for swallow evaluation and feeding tube discussion)
- Rapid weight loss despite adequate intake (signals disease progression and increased metabolic demands)

- Severe agitation, aggression, or psychosis (requires urgent psychiatric evaluation and medication adjustment)

What the care team will do

- Monitor for chorea (involuntary jerky movements) and fall risk
- Assess swallowing ability and aspiration risk at every meal
- Screen for depression, suicidal ideation, and psychiatric symptoms daily
- Coordinate speech therapy for communication strategies as slurred speech (dysarthria) (slurred speech) progresses
- Ensure adequate caloric intake and monitor weight weekly
- Provide family education about genetic inheritance and testing options
- Assess and manage medication side effects, especially from antipsychotics and dopamine-blocking agents
- Support advance care planning early in the disease course

Medicines you may be given — and why

Tetrabenazine

Tetrabenazine blocks VMAT2 proteins inside nerve cells. VMAT2 normally packages dopamine (a movement-controlling chemical) into storage bubbles. Blocking VMAT2 reduces dopamine release, which decreases excessive involuntary movements.

Deutetrabenazine

Deutetrabenazine works exactly like tetrabenazine to block dopamine storage in nerve cells. The deuterium (heavy hydrogen) substitution slows drug breakdown in the liver, allowing twice-daily dosing instead of three times daily and causing fewer peak-related side effects.

Sertraline or citalopram

SSRIs block the pump that pulls serotonin (a mood-regulating chemical) back into nerve cells after release. This leaves more serotonin in the space between nerve cells, strengthening mood-control signals in the brain. Over weeks, this lifts depression and reduces anxiety and irritability.

Olanzapine or risperidone

These drugs block dopamine receptors (landing sites for dopamine) in multiple brain areas. In the striatum, dopamine blockade reduces chorea. In frontal and limbic areas, the drugs calm

agitation, psychosis, and severe irritability by dampening overactive dopamine and serotonin signals.

Percutaneous endoscopic gastrostomy (PEG) tube feeding

A PEG tube is a flexible tube inserted through the abdominal wall into the stomach. It allows direct delivery of liquid nutrition when swallowing becomes too dangerous. This prevents aspiration pneumonia (lung infection from inhaling food) and provides consistent calories to maintain weight and hydration.

Amantadine

Amantadine blocks NMDA receptors (glutamate-activated channels) on nerve cells and increases dopamine release and blocks dopamine reuptake. This dual action can reduce chorea in some patients, though the exact mechanism in Huntington disease is not fully understood. It may also improve rigidity if present.

Where this information comes from

- Huntington Study Group and European Huntington Disease Network guidelines on clinical management of Huntington disease (2020)
- American Academy of Neurology practice guideline on genetic testing and counseling for Huntington disease (2019)
- National Institute of Neurological Disorders and Stroke (NINDS) Huntington Disease Information Page (2023)
- Huntington Disease Society of America nursing and care management recommendations for Huntington disease patients and families (2021)

Last reviewed: 2026-08-29