

# Huntington's Disease: The Need for a Cure

**Uncontrollable movements. Memory loss. Personality changes. Difficulty eating and drinking.**

These are all common experiences for patients with Huntington's disease, making independent living and interpersonal relationships tremendously difficult.



## About Huntington's Disease

Huntington's is an inherited, relentlessly progressive neurodegenerative disease caused by a genetic mutation. Deposits of abnormal protein in the brain lead to psychiatric and movement disorders, and ultimately death.

The first symptoms to show are typically mood disorders, such as depression and anxiety. Involuntary movements of the limbs and trunk usually follow. Most patients will experience symptom onset between age 35 and 45, and the disease is usually fatal within 20 years.

## Treatment

There is no cure for Huntington's, nor are there treatments to slow, stop or reverse disease progression. Potential cures are currently being investigated in clinical trials, but definitive breakthroughs have been elusive.

There are, however, some medications that address symptoms. Medications may reduce involuntary movement. Antidepressants and anti-anxiety medications can improve common psychiatric symptoms. Antipsychotics may help with more advanced psychiatric symptoms, such as hallucinations and behavioral challenges.



Non-pharmacological approaches to symptom management can also improve quality of life for patients with Huntington's. Speech therapy and nutritional supplements, for example, may improve eating and combat weight loss and malnutrition associated with swallowing difficulty. Physical and occupational therapy can combat loss of muscle strength and coordination, helping patients maintain independence for daily activities.

Despite the lack of disease-modifying medications, patients deserve the best possible quality of life. This makes access to the full range of treatments all the more important.

Huntington's disease is relentlessly progressive and causes years of disability, leading to early death.

**While policymakers and researchers focus on finding a cure, patients deserve access to treatments that can reduce symptoms and improve their daily lives.**

## The Need for Innovation

Treating symptoms is helpful, but a cure is needed for this fatal disease. Policymakers can help by providing greater funding for research that will lead to innovative treatments. They can also increase patient participation in clinical trials by crafting policies that reduce barriers to enrollment, such as missed work, travel expenses and lack of caregiver support.

When research yields positive results, policymakers can find ways to ensure patients have access to innovative treatments. In the meantime, policies that support access to available care are critical.



**Alliance for  
Patient Access**

The Alliance for Patient Access is a national network of policy-minded health care providers advocating for patient-centered care.

[AllianceforPatientAccess.org](http://AllianceforPatientAccess.org)



The Movement Disorders Policy Coalition brings together advocacy groups, health care providers, patients and other stakeholders to inform policy impacting patient-centered care for people living with movement disorders.

[MovementDisordersPolicy.org](http://MovementDisordersPolicy.org)

