Cognitive Caring
BRAIN CARE, HUMAN CARE

Huntington's Disease (Huntington's Dementia): A Guide for Patients & Families

Huntington's disease is a genetic brain disorder that causes progressive changes in movement, thinking, and behavior. It is caused by a change in a specific gene and can be passed down in families. Over time, individuals may develop cognitive decline (sometimes called Huntington's dementia), as well as mood and movement symptoms. While there is no cure, treatment and supportive care can help manage symptoms and improve quality of life.

Common Signs & Symptoms

- Involuntary movements (chorea)
- Difficulty with coordination or balance
- Memory problems and slowed thinking
- Difficulty planning or organizing tasks
- Mood changes such as depression or irritability
- Anxiety or emotional instability
- Changes in judgment or behavior

How Huntington's Disease Progresses

- Early Stage: subtle movement changes, mood symptoms, mild cognitive changes
- Middle Stage: more noticeable movement problems, difficulty with daily tasks, worsening cognition
- Late Stage: severe movement impairment, significant cognitive decline, need for full assistance

Genetic Considerations

- Huntington's disease is inherited in an autosomal dominant pattern
- Each child of an affected parent has a 50% chance of inheriting the condition
- Genetic testing is available but should be discussed carefully with healthcare providers

Diagnosis

- Clinical evaluation of symptoms and family history
- Genetic testing to confirm the diagnosis
- Brain imaging and cognitive testing to assess disease progression

Treatment & Management

Symptom Management

- Medications for movement symptoms
- Treatment of depression, anxiety, or irritability
- Medications for behavioral symptoms when needed

Supportive Care

- Physical therapy for movement and balance
- Occupational therapy for daily functioning
- Speech therapy for communication and swallowing
- Structured routines and supportive environments

Safety Considerations

- Fall prevention and home safety
- Monitoring for swallowing difficulties
- Supervision as cognitive symptoms progress
- Monitoring for mood changes or suicidal thoughts

When to Seek Medical Attention

- Worsening movement or balance problems
- Significant mood or behavioral changes
- Difficulty eating or swallowing
- Increased confusion or functional decline
- Signs of depression or suicidal thoughts

National Organizations & Resources

✓ Huntington's Disease Society of America (HDSA)
🌐 hdsa.org

✓ National Institute of Neurological Disorders and Stroke (NINDS)
🌐 ninds.nih.gov

✓ National Institute of Mental Health (NIMH)
🌐 nimh.nih.gov

✓ Eldercare Locator
📞 1-800-677-1116 | 🌐 eldercare.acl.gov

Final Notes

- Huntington's disease affects movement, thinking, and behavior over time.
- It is a genetic condition that can impact multiple family members.
- Supportive care and early planning can help maintain quality of life.