

more  
than HD

Huntington's disease and HD chorea won't define  
my story would go.

HD's physical and mental effects are difficult.  
The progression of the disease is unpredictable.

But I won't let HD and HD chorea define my story.

When I feel alone, I'll remember my HD community  
and everyone on my side.

When I feel scared, I'll remind myself of my strength  
and how far I've come.

When I feel limited by the disease, I'll do everything  
I can to continue to make the most of my today  
and tomorrows.

Huntington's disease and HD chorea isn't how I lived  
my story would go—but my story's not over yet.

100

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# THERE'S MORE TO YOUR STORY THAN HD

Don't let an HD diagnosis or symptoms like chorea  
define your next chapter

Learn what to expect, the importance of community, and how  
to help manage chorea and other symptoms

# MOVING FORWARD WITH YOUR HD DIAGNOSIS

A diagnosis of HD can come with  
a lot of emotions:



**Shock**



**Anger**



**Denial**

You may even feel relief after confirming  
what you already suspected or feared.  
These feelings are all normal.

If you or a loved one has seen a family member struggle with HD, it can be difficult to imagine that your experience will be different.

However, every experience with HD is unique.

Research into the management of HD and HD chorea continues to advance. Today there are more options than ever before.

**HD may be part of your story, but it's not the whole story. Now that you have a diagnosis, you get to choose how to move forward.**

In this next chapter, you have a say in how you decide to live with HD.



**Don't let a diagnosis of HD or symptoms like chorea define what's possible for you. Let it be a starting point.**

There is much to understand about living with HD. Not only about the symptoms, including chorea, and how they can be treated, but also how to create a community of support for the journey ahead.

By educating yourself on HD and HD chorea as early as possible, you and your support team can plan what to do today to make the most of your tomorrows.

# BUILDING A CARE TEAM FOR THE JOURNEY AHEAD

**Creating a community of support is an important step after diagnosis or a positive test result.**


Your care team may include professionals who are experts in different areas of medicine and healthcare. Together, you can create a plan that can best support your unique situation and goals.

Care teams can vary in size and scope.

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**Some core members of your care team may include:**

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**Neurologist**  
Specializes in disorders of the brain and nervous system

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**Psychiatrist**  
Specializes in mental health

**Your care team may also include other professionals who can provide additional support based on your specific needs, like:**



**Social worker**

Helps guide you during your journey with HD; assists with disability and financial planning, finding community support groups, and short-term or long-term care coordination

You may benefit from finding a care team with experience in managing HD and symptoms like chorea. Some care settings have specialized care teams who have experience working with families affected by HD.

Learn more about building a care team and additional healthcare providers and professionals who can help at [MoreThanHD.com/Care-Team](https://www.morethanhd.com/care-team)



# CONNECTING WITH THE HD COMMUNITY

**It's important to know that you don't have to be alone on your HD journey.**

Family, friends, and the members of the HD community can provide support beyond your care team.

It can be a great relief to connect with other people and families affected by HD. They can provide emotional support, valuable advice, and a sense of community.



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The HD community is very active. And support groups and individual mentorship opportunities are available across the US and online. Some include:



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HD Reach



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Help 4 HD International



**Huntington's Disease  
Society of America**

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Huntington's Disease Society  
of America (HDSA)



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Huntington's Disease Youth  
Organization (HDYO)

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## UNDERSTANDING THE SYMPTOMS OF HD

**HD is an inherited disease that causes nerve cells in the brain to gradually break down.**

Over time, this damage causes symptoms that can disrupt everyday life—physically, mentally, and emotionally.

**The 3 Ms: Movement, Mind, and Mood are an easy way to remember the 3 main ways possible HD symptoms affect people.**



HD is a disease that has the potential to affect every part of you. **The possible symptoms can be divided into 3 main areas:**



### **MOVEMENTS**

Uncontrolled movements (like chorea) and problems with walking, balancing, or moving around safely



### **MIND**

Forgetfulness and difficulty with thinking, paying attention, and making decisions



### **MOOD**

Personality changes, depression, low or no motivation, irritability, and emotional reactions

Symptoms will vary from person to person, as everyone's journey with HD is unique.

**~90%**

**Almost everyone with HD will experience chorea.**

The term chorea (cor-EE-uh) comes from the Greek word that means "to dance." These involuntary, uncontrollable movements can make it look like you're dancing, restless, or fidgety.

# UNDERSTANDING THE STAGES OF HD

The symptoms of HD usually start between the ages of 30 and 50. But people can develop HD symptoms at any age. In some families, symptoms may be seen earlier with each generation.

Just because you have an HD diagnosis doesn't mean that all symptoms will appear at once or at all. **HD is a progressive disease**, and over time the symptoms of HD may get more noticeable, worsen, or change.

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## The progression of HD can be understood in 3 stages:

### Early Stage

- Chorea can present in early stages as clumsiness, tripping, dropping, or bumping into things
- It may be difficult to think through things or control feelings or behavior; some people may feel depressed or anxious
- Living and working without help from others may be possible



## Middle Stage

- Chorea may cause disruptive jerking and twisting movements, issues with swallowing and balance, and an increase in falling and weight loss
- It may become difficult to understand, remember, or act on things; some people may experience changes in sleeping patterns and their personality
- Help may be needed to do daily activities, like eating, getting dressed, and bathing; most people are unable to work or drive

## Late Stage

- Chorea can worsen or be replaced with stiff and slow movements
- The ability to talk or communicate may be lost
- Full-time help in daily living is typically needed; some people may need to use a wheelchair or stay in bed



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## Movements

# HD CHOREA AND ITS IMPACT

Chorea is a defining symptom of HD because it is so common. It is also often the first visible symptom of HD.

### **Chorea movements may include:**

Uncontrolled twisting or jerking

Shoulder shrugging

Flailing arms or legs

Finger flicking

Facial twisting

Excessive blinking

The movements can be small or large and tend to get worse with stress. They can also worsen or change over time.

**When chorea gets worse, it can make everyday activities and self-care more difficult, such as:**



Walking &  
balance



Talking &  
swallowing



Bathing &  
getting  
dressed



Shopping &  
other daily  
activities

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Chorea isn't just the most common symptom of HD—for many, it is also considered one of the most impactful.\* Chorea can affect your independence and quality of life.

**~90%**

In a survey, **~90%** of people with HD **experienced chorea** on their journey

**99%**

**99%** of people with HD chorea in the survey **required assistance** with some activities of self-care<sup>†</sup>

According to one survey, **most people with HD and their caregivers said it was very important to manage chorea.**

Loss of independence was one of the most common reasons given for saying that chorea was important to treat.

\*In an HDSA survey, HD patients and caregivers were asked to identify HD symptoms that had the biggest impact on daily life. Of 2591 respondents, 30% of caregivers and 17% of HD patients reported chorea symptoms as the most impactful.

†Results based on a survey of 144 healthcare providers and 427 people with HD.

# TALKING TO YOUR CARE TEAM ABOUT CHOREA

HD chorea affects people differently. It can be hard to describe what you're experiencing.

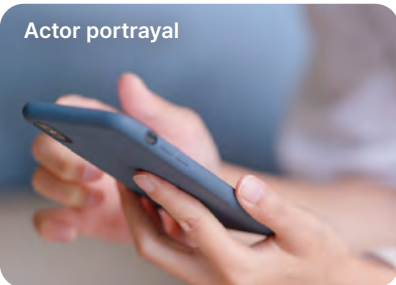
## **Ask yourself the following questions:**

- Has your handwriting changed?
- Do you have trouble typing or using a cell phone or remote control?
- Are you dropping things? Or finding yourself tripping or bumping into things?
- Do you have trouble getting dressed?
- Are you slurring your speech? Or having trouble talking or swallowing?

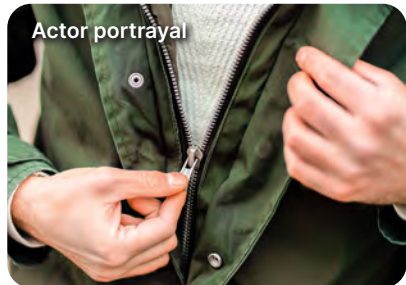
**If you have experienced any of the above, it may be chorea.**

It can be helpful to ask a loved one if they have noticed any movements, too.

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Actor portrayal





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**Below are some additional talking points to consider when discussing your movements with your healthcare provider:**

- The location of your movements
- When these movements started, and how often you have them
- If others, like your family or friends, have noticed your movements
- How these movements affect your daily routine
- How these movements affect your mind and your mood
- How these movements affect your relationship with others, like family or coworkers

Consider bringing your caregiver or another trusted person into conversations with your care team. They may have additional insight into your HD symptoms and how they are impacting you.

**Together, you can create a symptom management plan that is right for you and your goals. So, you can continue to make the most of your life with HD.**

## Mind and Mood

# ADDITIONAL SYMPTOMS OF HD

**Remember that HD is a disease that has the potential to affect every part of you.**

Over time, HD causes nerve cells in the brain to break down. These changes don't just affect your ability to control movements. You may also find it difficult to think or control your emotions and behavior.

While they are not always obvious, changes to the way you think and behave can be some of the earliest symptoms of HD. You may even experience these changes before you begin to have movement problems.

These symptoms can be distressing, both for you and your loved ones.



### **Symptoms impacting your mind may cause difficulties with:**

- Paying attention
- Controlling urges
- Managing your temper
- Learning or remembering new things
- Starting or ending activities
- Obsessing over a thought or idea





**Symptoms impacting your mood and behavior may cause difficulties like:**

- Having low or no motivation
- Becoming anxious or agitated
- Feeling sad or depressed
- Acting recklessly or without thinking
- Having emotional reactions
- Feeling isolated

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Sometimes, symptoms in one area can affect symptoms in another area. For example, if you're having difficulty talking and swallowing, it may trigger an emotional reaction.

Understanding the bigger picture of HD can help you and your loved ones make connections between symptoms. This can be important when creating symptom management goals.

That's why it's so important to tell your healthcare provider and the rest of your care team about all the symptoms you experience and how they are impacting your daily life.

# KNOWING YOUR SYMPTOM TREATMENT OPTIONS

While there is no cure for HD, there are medications that can help relieve some of the symptoms of HD, like chorea.

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Whether your symptoms are mild, moderate, or severe, the first step in taking action is talking with your care team.

Your healthcare provider can help you understand your treatment options for specific symptoms and discuss the goals of treatment.

**The goals of your care plan are personal to you. You have a say in deciding what your goals are and how you plan to achieve them.**

**For example, the goals of treatment for HD symptoms could be:**



**Reducing symptoms**



**Improving function**



**Maximizing quality of life**



**VMAT2 inhibitors are FDA-approved medications used to treat chorea associated with Huntington's disease.**

That means these medications have been studied specifically in people with HD chorea and are proven to be effective in reducing chorea movements.

Learn more about VMAT2 inhibitors and a treatment option at [MoreThanHD.com/VMAT2](https://www.morethanhd.com/vmat2)

**There are many medications developed for other disorders that are used to help treat additional symptoms of HD.**

For example, certain mental health medications may also be used to help manage emotional symptoms.

Always discuss your mental health symptoms and concerns with your healthcare provider, including if these medications could be right for you.

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# CAREGIVING FOR A LOVED ONE WITH HD

Becoming a caregiver for someone with HD is a role that comes with its own challenges and rewards. Caregiving is an act of courage, love, and sacrifice.

You are a vital part of your loved one's journey with HD. Your responsibilities will progress as the disease does, so it is important to know that there is support and community for caregivers like you.

## Some ways to educate yourself and be an advocate for your loved one along their HD journey:



- Plan ahead and keep copies of important info like doctors' contacts, insurance details, and appointment dates

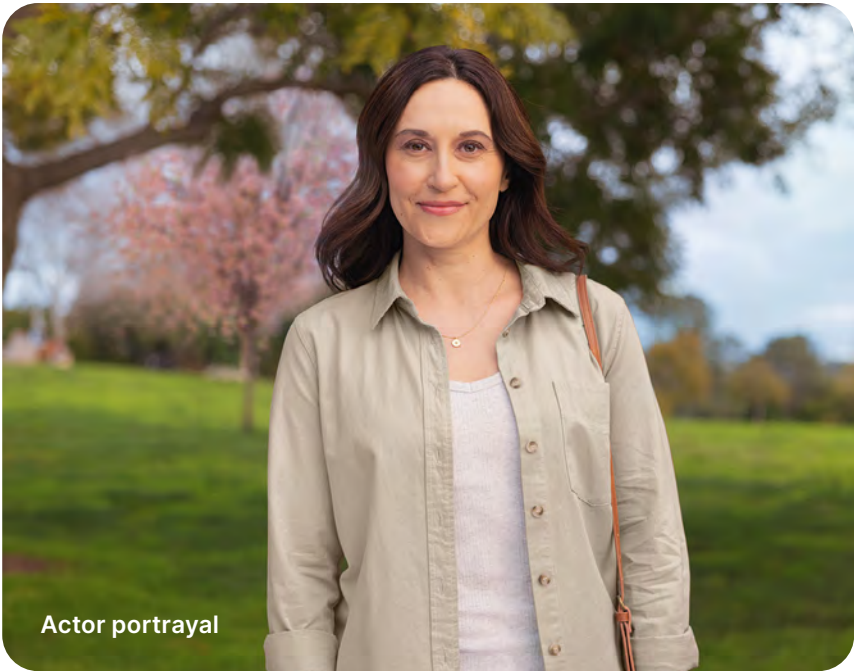


- Identify local and online resources and reach out for support early and often



- Take time to care for yourself so you can continue to care for your loved one

Find more information and tips for caregivers at [MoreThanHD.com/Caregiver](https://www.morethanhd.com/caregiver)



It can be easy to feel overwhelmed by the pressures of caring for a loved one with HD—and yourself. But you are not alone. The HD community is strong and active, and support groups are available to help caregivers and families too.

- Caregiver Action Network
- Family Caregiver Alliance
- HDSA
- National Alliance for Caregiving

Give yourself the time to find a group that works for you, so you don't have to handle this journey on your own. It can be a great relief to share your feelings and experiences with people who have faced the same challenges—and achievements.

# CARE TEAM CONTACT LIST

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Phone # \_\_\_\_\_

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Specialty \_\_\_\_\_

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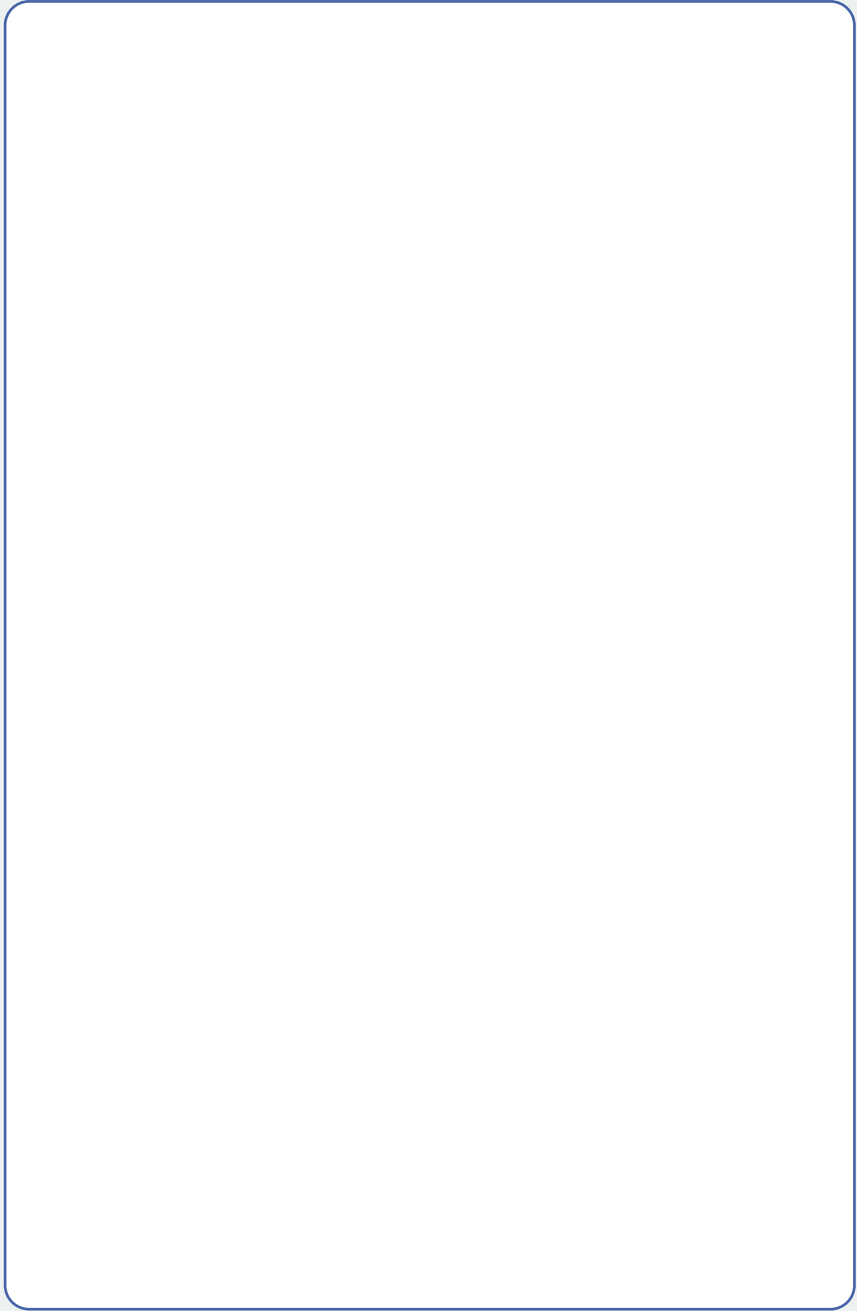
# HD SYMPTOM MANAGEMENT GOALS

Use this space to help make the most of your tomorrows by planning today when and how to address symptoms of HD, like chorea.

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# NOTES



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**Don't let your HD diagnosis or symptoms like chorea define what's possible for you.**

Talk to your healthcare provider today and make a plan for your journey with HD.

Learn more about maximizing what's possible despite an HD diagnosis at [MoreThanHD.com](https://www.morethanhd.com)