

STARTING THE CONVERSATION EARLY CAN MAKE ALL THE DIFFERENCE

When talking to a healthcare provider, it's important to be prepared to have a productive conversation about symptoms you or your loved one may be experiencing. Even if uncontrollable movements are not being experienced yet, the conversation can still be started early to be ready for managing what comes next.

Talking to your healthcare provider

Before your or your loved one's next appointment, answer the questions below. They will help describe HD chorea symptoms and the impact the uncontrollable movements have on the daily life of you or your loved one. If you personally are experiencing HD chorea symptoms, you can ask your care partner or a loved one to attend the appointment with you. They can offer support while you talk with your healthcare provider about these movements and the impact HD chorea is having on your daily life.

Including minor instances, where are you experiencing uncontrollable movements? (Check all that apply.)

Face, mouth, or jaw Hands and/or fingers Feet and/or toes Legs Arms Torso None

How often do these movements occur?

Multiple times per minute Multiple times per hour Multiple times per day Other _____

Do you experience any of the following because of your movements? (Check all that apply.)

Stress Embarrassment Isolation Pain and discomfort Anxiety Difficulty sleeping
Frustration Other _____

Planning ahead

People with HD say losing their independence is one of the most frustrating parts of living with chorea. Thinking ahead about how these uncontrollable movements may impact the daily life of you or your loved one can help preserve independence.

What are the things that you enjoy doing or are important to you in your everyday life? Make sure to even write down the little things (sports, volunteering, crafting, etc).

How would **uncontrollable movements** interfere with the everyday activities you mentioned above?

What would be the tipping point for you to talk to your healthcare provider about HD chorea treatment options?

Planning & Discussion Guide

Understanding HD chorea

Asking the following questions during the appointment can help you or your loved one learn more about HD chorea and available treatment options to help preserve independence.



When asking these questions, make sure you or a care partner take notes to reference later.
If your healthcare provider gives you an answer that isn't clear, ask them to clarify.

What causes chorea?

Will chorea go away on its own?

Will chorea get worse?

How do you assess the severity of chorea?

What are my HD chorea treatment options? Which treatment would you recommend and why?

After starting treatment, when can I expect to see results?

What are our next steps?



Learn more about the
impact of HD chorea at
HonestlyHD.com