

Planning ahead can make all the difference

When it's time to talk with your doctor about HD chorea, make sure you're equipped to have a productive conversation about your symptoms.

Making a plan

People with HD say the loss of self-reliance is one of the most frustrating things about having chorea. That's why, even if you're not experiencing involuntary movements yet, it's important to start a conversation with your doctor early on about HD chorea so you can be prepared for the future.

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 (exercising, going out to eat, using your phone, etc.)?

What **specific movements** might interfere with doing these things?

Thinking ahead, when will you know **it's time to talk to your doctor about treatment for your HD chorea?**

Talking to your doctor

Once you've decided it's time to talk to your doctor, the questions below are meant to help guide how you describe your HD chorea and the impact the involuntary movements have on your daily life.

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

- | | |
|--|-----------------------------|
| <input type="radio"/> Face, Mouth, or Jaw | <input type="radio"/> Torso |
| <input type="radio"/> Hands and/or Fingers | <input type="radio"/> Arms |
| <input type="radio"/> Feet and/or Toes | <input type="radio"/> Legs |

2 How often do these movements occur?

- | |
|---|
| <input type="radio"/> Multiple times per minute |
| <input type="radio"/> Multiple times per hour |
| <input type="radio"/> Multiple times per day |
| <input type="radio"/> Other |

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

- | | |
|-----------------------------------|---|
| <input type="radio"/> Stress | <input type="radio"/> Embarrassment |
| <input type="radio"/> Isolation | <input type="radio"/> Pain & discomfort |
| <input type="radio"/> Anxiety | <input type="radio"/> Difficulty sleeping |
| <input type="radio"/> Frustration | <input type="radio"/> Other |

Tip: If comfortable, ask your care partner or a loved one to attend the appointment with you. They can offer support while you talk with the doctor about these movements and the impact HD chorea is having on your daily life.

Talking with your doctor

Once you have decided it's time to talk to your doctor, the following questions are meant to help you learn more about HD chorea and the treatment options that are available to help preserve your independence.



When asking these questions, make sure you or a care partner take notes to reference later or write down any concerns you may have. **And if your doctor gives you an answer that isn't clear, ask them to clarify.**

1 What causes chorea?

NOTES: _____

2 Will chorea go away on its own?

NOTES: _____

3 Will chorea get worse?

NOTES: _____

4 How do you assess the severity of chorea?

NOTES: _____

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

NOTES: _____

6 How long after starting treatment before I see a difference in my chorea?

NOTES: _____

7 What are our next steps?

NOTES: _____
