



HD Chorea Independence Planner

You and/or your care partner can use your responses below to continue to develop a plan to maintain independence once HD chorea arises. Be sure to share your plan with your doctor, so they are aware of your decisions and can offer guidance on your plan.

Mark your responses:

1. What are some tasks or activities you do every day that you want to keep doing on your own for as long as possible?

(Select all that apply)

- Bathing and other personal grooming tasks
- Dining out
- Exercising or participating in sports
- Gardening
- Getting dressed
- Playing a musical instrument
- Preparing meals/Cooking food
- Taking walks/Walking the dog
- Traveling
- Using your computer, phone, or tablet
- Other



These activities, and others that might not be listed, are important to you in your daily routine. You'll use these to determine your chorea threshold in question #3.

HD Chorea Independence Planner

2. Are you concerned that your ability to perform these tasks and activities might be affected by chorea?

Yes

Unsure, I haven't considered it yet

No



Thinking about and planning how you'll adapt to daily life once HD chorea begins is important. If you decide to pursue treatment in the future, treatment may help to reduce movements and allow you to continue with the activities that are important to you.

3. Are you open to pursuing treatment to help maintain your independence?

Yes, I'm open to treatment

No, I do not want to treat with medication

I haven't thought about it before

Unsure, I'd need to do more research



Deciding now about pursuing treatment in the future may be difficult, but that's okay. Just know treatment is available.

HD Chorea Independence Planner

4. Do you know at what point you would begin to consider treating HD chorea?

- As soon as I notice movements
- When chorea starts to impact my daily activities
- Unsure

Determining your chorea threshold is a critical part of your plan to maintain independence. Here's how to determine yours:

- 1 Select one of the activities in question #1, an activity you want to do on your own for as long as possible.
- 2 Think about and write down how severe chorea's impact must be on your ability to do this activity to trigger a conversation with your doctor.

For example: "Taking walks." If you have difficulty tying your shoes as you prepare to go for a walk, is that enough to cause you to schedule an appointment with your doctor? Or would tripping while taking a walk be what causes you to speak to your doctor?

With your care partner/family, feel free to determine your chorea threshold for other activities on your list.

5. Although you're not experiencing movements now, it's important to check and reassess on a regular basis. How often would you like to check for the movements of HD chorea?

- Monthly
- Every four months
- Twice a year
- When I or a loved one notices symptoms



Ask your care partner/family to help monitor your ability to do the things on your list from question #1. Sometimes, the movements of chorea can be dismissed as something else, so it's good to have this reminder to keep a closer eye on how you're doing or to check to see if movements are occurring.

HD Chorea Independence Planner

6. Are you open to your doctor and/or care partner reminding you it's time to discuss treatment when it becomes more difficult to perform daily tasks or activities?

Yes, I'd like them to remind me when it's time to discuss treatment

No, I'd like to bring it up to my doctor or care partner on my own



Chorea symptoms sometimes begin around the same time as speech becomes affected, mood swings arise, and balance issues occur. **With several symptoms happening at once, it's important to get your care partner's/family member's input on your ability to perform daily activities.** This can be helpful in determining when it is time to discuss treatment with your doctor.

When movements of HD chorea begin, it's important to keep track of where movements in the body occur, how often they occur, and their impact on your ability to perform daily activities. **The Doctor Discussion Guide can help you note this information and can help you and your doctor determine if it's time to begin treatment for HD chorea.**



Planning ahead with your care partner or family members can help maintain your independence for as long as possible. Talk to your doctor for more information about planning for independence and treatment options for HD chorea.