

# **Huntington's Disease**

# Questions to Help Determine Symptoms and Limitations

## **Cognitive Symptoms**

- 1. When did you start experiencing symptoms of HD (even if you did not know they were HD related)?
- 2. What are your main symptoms of HD?
- 3. Do you have difficulty learning new things?
- 4. Are you able to read?
  - a. What kinds of things do you read?
  - b. How often do you read?
  - c. Do you think you would be able to read an entire novel, like a 200 page book?
  - d. Would you be able to listen to a book on tape?
- 5. Do you have problems with memory?
  - a. What is worse, short term or long term?
  - b. What kinds of problems have you experienced with your memory?
  - c. If you had multiple appointments in a given week would you be able to keep track of where you needed to be and when?
  - d. How do you keep track of places you need to be and things you need to do?
  - e. Does someone specific remind you, do you use a calendar?
  - f. What kinds of things do you need to be reminded to do?
- 6. How long can you concentrate at one time?
  - a. 30 minutes? 60 minutes? 2 hours?
- 7. Do you have trouble with motivation?
- 8. Do you have difficulty following instructions?
- 9. Are you able to finish what you started?
  - a. If you started a puzzle, would you be able to finish it?
- 10. Have you shown any signs of change in personality or mood?
  - a. Example?
  - b. Did you change from an outgoing person to a quiet person?
  - c. Do you any trouble with impulsivity?
- 11. Are you able to go out by yourself?
- 12. Would you be able to work at a job with people?
- 13. Anywhere you go on a regular basis?

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#### **Physical Symptoms**

- 1. When did you first start experiencing involuntary movements/chorea?
- 2. In what parts of your body do you experience chorea?
- 3. Describe your chorea/involuntary movements.
- 4. How is your balance and coordination?
  - a. Do you have any difficulties with stairs?
  - b. Do you have any difficulty walking?
  - c. Do you trip or fall? How often?
  - d. Are there specific things that trigger a fall?
  - e. Do you use an assistive device?
  - f. Has a doctor recommended an assistive device?
- 5. Does anything make it better? Worse?
- 6. Are you taking medication for your chorea?
- 7. Does the chorea in your hands and arms give you difficulty?
  - a. Do you drop things?
  - b. How often do you drop things?
  - c. What kinds of things do you drop?
  - d. Do you have trouble holding a knife and fork?
- 8. How long have you had trouble using your hands?
  - a. Are you able to tie tennis shoes?
  - b. Are you able to shave?
  - c. Are you able to write? Is your handwriting legible?
  - d. Do you think you would be able to write someone a letter?
- 9. Have you ever injured yourself because of your chorea?
  - a. Example?
- 10. Has your chorea impacted your ability to work?
- 11. Do you have any issues with choking?
  - a. Is there any food that you choke on or have difficulty eating?

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### **Activities of Daily Living**

- 1. Do you need help with personal care?
- 2. What help do you need with personal care?
  - a. Do you have trouble getting dressed?
  - b. Do you need to sit down to put on pants?
  - c. Do you need help with buttons or zippers?
  - d. Do you need a shower stool or shower bar?
- 3. What chores are you able to complete now, without assistance?
  - a. Do you need help or reminders when completing chores?
  - b. Do you need to take breaks when completing chores?
  - c. Do you forget steps when completing chores?
  - d. How many chores can you complete in a day?
- 4. Are you able to cook for yourself?
  - a. What do you cook for yourself?
  - b. Do you prepare meals from scratch or do you prepare frozen/pre-made meals?
  - c. Any snacks you prepare for yourself?
  - d. Do you use the microwave?
  - e. Do you use the stove or oven?
  - f. Could you follow a recipe from start to finish?
- 5. Have your hobbies changed because of your HD?
  - a. What has changed?
  - b. What are your hobbies now?
- 6. Do you have good days and bad days?
  - a. Describe a good day.
  - b. Describe a bad day.
  - c. How many bad days do you have a month?

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