

RESPONSES TO STRESS

This is a list of things about having Huntington's disease that people sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for you in the past 6 months.

	Not at All	A Little	Somewhat	Very
a. Progressive loss of communication skills	1	2	3	4
b. Concerns about my future	1	2	3	4
c. Financial concerns	1	2	3	4
d. Stress from growing up with HD	1	2	3	4
e. The effect of HD on my family members	1	2	3	4
f. Feeling isolated from friends or family members	1	2	3	4
g. Loss of independence/ability to care for self and dependents	1	2	3	4
h. Loss of control over my emotions	1	2	3	4
i. Grieving over my life with HD	1	2	3	4
j. Other: _____	1	2	3	4

Circle the number that shows how much control you generally think you have over these problems.

1 2 3 4
 None A little Some A lot

Below is a list of things that people sometimes do, think, or feel when they are dealing with Huntington's disease. Everyone copes in their own way--some patients do a lot of the things listed below, other people just do or think a few things.

Think of all the stressful parts of having Huntington's disease you checked off above. For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** you do or feel these things when you are trying to deal with these things. Please let us know about everything you do, think, and feel, even if you don't think it helps make things better.

WHEN DEALING WITH HUNTINGTON'S DISEASE:	How much do you do this?			
	Not at all	A little	Some	A lot
1. I try not to have any emotions.	1	2	3	4
2. When dealing with Huntington's disease, I feel sick to my stomach or get headaches.	1	2	3	4
3. I try to think of different ways to deal with stress related to having Huntington's disease. Write one plan you thought of: _____ _____	1	2	3	4
4. When faced with the stress of having Huntington's disease, I don't feel any emotions at all, it's like I have no feelings.	1	2	3	4
5. I wish that I were stronger and less sensitive so that things would be different.	1	2	3	4
6. I keep remembering what has happened with my Huntington's disease or can't stop thinking about what might happen	1	2	3	4
7. I let someone or something know how I feel. (<i>remember to circle a number.</i>) →	1	2	3	4
Check all you talked to:				
<input type="checkbox"/> Spouse/Partner	<input type="checkbox"/> Friend	<input type="checkbox"/> Physician	<input type="checkbox"/> Brother/Sister	<input type="checkbox"/> Clergy Member
<input type="checkbox"/> My Children	<input type="checkbox"/> Parent	<input type="checkbox"/> Nurse	<input type="checkbox"/> Therapist/Counselor	<input type="checkbox"/> None of these

WHEN DEALING WITH HUNTINGTON'S DISEASE:

How much did you do this?
Not at all A little Some A lot

	1	2	3	4
8. I decide I'm okay the way I am, even though I'm not perfect.				
9. When I'm around other people I act like the Huntington's disease never happened.	1	2	3	4
10. I just have to get away from everything when I am dealing with the stress of having Huntington's disease.	1	2	3	4
11. I deal with the stress of having Huntington's disease by wishing it would just go away, that everything would work itself out.	1	2	3	4
12. I get really jumpy when I am dealing with the stress of having Huntington's disease.	1	2	3	4
13. I realize that I just have to live with things the way they are.	1	2	3	4
14. When I am dealing with the stress of having Huntington's disease, I just can't be near anything that reminds me of what is happening.	1	2	3	4
15. I try not to think about it, to forget all about it.	1	2	3	4
16. When I am dealing with the stress of having Huntington's disease, I really don't know what I feel.	1	2	3	4
17. I ask other people or things for help or for ideas about how to make things better (remember to circle a number.) →	1	2	3	4
Check all you talked to:				
<input type="checkbox"/> Spouse/Partner <input type="checkbox"/> Friend <input type="checkbox"/> Physician <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Clergy Member				
<input type="checkbox"/> My Children <input type="checkbox"/> Parent <input type="checkbox"/> Nurse <input type="checkbox"/> Therapist/Counselor <input type="checkbox"/> None of these				
18. When I am trying to sleep, I can't stop thinking about the stress of having Huntington's disease, or I have bad dreams about having Huntington's disease.	1	2	3	4
19. I tell myself that I can get through this, or that I will be okay.	1	2	3	4
20. I let my feelings out. (remember to circle a number.) →	1	2	3	4
I do this by: (Check all that you did.)				
Writing in my journal/diary <input type="checkbox"/> Drawing/painting <input type="checkbox"/>				
Complaining to let off steam <input type="checkbox"/> Being sarcastic/making fun <input type="checkbox"/>				
Listening to music <input type="checkbox"/> Punching a pillow <input type="checkbox"/>				
Exercising <input type="checkbox"/> Yelling <input type="checkbox"/>				
Crying <input type="checkbox"/> None of these <input type="checkbox"/>				
21. I get help from other people or things when I'm trying to figure out how to deal with my feelings. (remember to circle a number.) →	1	2	3	4
Check all you talked to:				
<input type="checkbox"/> Spouse/Partner <input type="checkbox"/> Friend <input type="checkbox"/> Physician <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Clergy Member				
<input type="checkbox"/> My Children <input type="checkbox"/> Parent <input type="checkbox"/> Nurse <input type="checkbox"/> Therapist/Counselor <input type="checkbox"/> None of these				
22. I just can't get myself to face the stress of having Huntington's disease.	1	2	3	4
23. I wish that someone would just come and take away the stress of having Huntington's disease.	1	2	3	4
24. I do something to try to fix the stressful parts of having Huntington's disease. (remember to circle a number.) →	1	2	3	4
Write one thing you did: _____ _____				
25. Thoughts about having Huntington's disease just pop into my head.	1	2	3	4

WHEN DEALING WITH HUNTINGTON'S DISEASE:

How much did you do this?
Not at all A little Some A lot

26. When I am dealing with the stress of having Huntington's disease, I feel it in my body. *(remember to circle a number.)* → 1 2 3 4

Check all that happen:

- My heart races My breathing speeds up None of these
I feel hot or sweaty My muscles get tight

You're half done! Before you keep working, look back at the first page so you remember the things about having Huntington's disease that have been stressful for you lately. Remember to answer these questions thinking about those things.

27. I **try** to stay away from people and things that make me feel upset or remind me of having Huntington's disease. 1 2 3 4

28. I don't feel like myself when I am dealing with the stress of having Huntington's disease, it's like I am far away from everything. 1 2 3 4

29. I just take things as they are, I go with the flow. 1 2 3 4

30. I think about happy things to take my mind off the stress of having Huntington's disease or how I'm feeling. 1 2 3 4

31. When the stressful parts of having Huntington's disease happen, I **can't stop** thinking about how I am **feeling**. 1 2 3 4

32. I get sympathy, understanding, or support from someone. *(remember to circle a number.)* → 1 2 3 4

Check all you went to:

- Spouse/Partner Friend Physician Brother/Sister Clergy Member
 My Children Parent Nurse Therapist/Counselor None of these

33. When the stressful parts of having Huntington's disease happen, I **can't** always control what I do. *(remember to circle a number.)* → 1 2 3 4

Check all that happen:

- I can't stop eating I can't stop talking
I do dangerous things I have to keep fixing/checking things
None of these

34. I tell myself that things could be worse. 1 2 3 4

35. My mind just goes blank when the stressful parts of having Huntington's disease happen, I can't think at all. 1 2 3 4

36. I tell myself that it doesn't matter, that it isn't a big deal. 1 2 3 4

37. When I faced with the stressful parts of Huntington's disease, right away I feel really: *(remember to circle a number.)* → 1 2 3 4

(Check all you feel.)

- Angry Sad Scared Worried/anxious
None of these

38. It's really hard for me to concentrate or pay attention when the stressful parts of having Huntington's disease happen. 1 2 3 4

39. I think about the things I'm learning from having Huntington's disease, or something good that will come from it. 1 2 3 4

40. After something stressful about Huntington's disease happens, I **can't stop** thinking about what I did or said. 1 2 3 4

41. When stressful parts of having Huntington's disease happen, I say to myself, "This isn't real." 1 2 3 4

WHEN DEALING WITH HUNTINGTON'S DISEASE:

How much did you do this?
Not at all A little Some A lot

42. When I'm dealing with the stressful parts of having Huntington's disease, I end up just lying around or sleeping a lot. 1 2 3 4
43. I keep my mind off stressful parts of having Huntington's disease by:
(remember to circle a number.) → 1 2 3 4
- Check all that you do:**
- Exercising Seeing friends Watching TV None of these
 Playing video games Doing a hobby Listening to music
44. When the stressful parts of having Huntington's disease happen, I get upset by things that don't usually bother me. 1 2 3 4
45. I do something to calm myself down when I'm dealing with the stress of having Huntington's disease.
(remember to circle a number.) → 1 2 3 4
- Check all that you do:**
- Take deep breaths Pray Walk
 Listen to music Take a break Meditate None of these
46. I just freeze when I am dealing with stressful parts of having Huntington's disease, I **can't** do anything. 1 2 3 4
47. When the stressful parts of having Huntington's disease happen, sometimes I act without thinking. 1 2 3 4
48. I keep my feelings under control when I have to, then let them out when they won't make things worse. 1 2 3 4
49. When stressful parts of having Huntington's disease happen, I can't seem to get around to doing things I'm supposed to do. 1 2 3 4
50. I tell myself that everything will be all right. 1 2 3 4
51. When stressful parts of having Huntington's disease happen, I **can't stop** thinking about **why** this is happening to me. 1 2 3 4
52. I think of ways to laugh about it so that it won't seem so bad. 1 2 3 4
53. My thoughts start racing when I am faced with the stressful parts of having Huntington's disease. 1 2 3 4
54. I imagine something really fun or exciting happening in my life. 1 2 3 4
55. When stressful parts of having Huntington's disease happen, I can get so upset that I can't remember what happened or what I did. 1 2 3 4
56. I try to believe that it never happened. 1 2 3 4
57. When I am dealing with the stress of having Huntington's disease, sometimes I **can't** control what I do or say. 1 2 3 4