

RESPONSES TO STRESS

This is a list of things about being from a family affected by Huntington's disease (HD), including being a spouse, partner, or caregiver of someone with HD that people sometimes find stressful or a problem to deal with. Please check-off the things that have been stressful for you lately.

	Not at All	A Little	Somewhat	Very
a. Taking on more responsibilities (household or caretaking)	1	2	3	4
b. Financial concerns	1	2	3	4
c. Concern for child's future HD diagnosis	1	2	3	4
d. Feeling isolated from friends and family	1	2	3	4
e. Living in a chaotic home environment	1	2	3	4
f. Feeling burned out due to long-term care-taking	1	2	3	4
g. Feeling guilty	1	2	3	4
h. Personality changes/aggression/violent mood swings in spouse/partner with HD	1	2	3	4
i. Grieving over the loss of spouse/partner (past or future)	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 being from a family affected by Huntington's disease. Everyone copes in their own way – some people do a lot of the things listed below, other people just do or think a few things.

Think of all the stressful parts of being from a family affected by 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 THE STRESS OF BEING FROM A FAMILY AFFECTED BY 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 being from a family affected by 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 being from a family affected by Huntington's disease. Write one plan you thought of: _____	1	2	3	4
4. When faced with the stress of being from a family affected by 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 family's 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

WHEN DEALING WITH THE STRESS OF BEING FROM A FAMILY AFFECTED BY HUNTINGTON'S DISEASE:

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

Check all you talked to:

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

8. I decide I'm okay the way I am, even though I'm not perfect. 1 2 3 4
 9. When I'm around other people I act like my family's 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 being from a family affected by Huntington's disease. 1 2 3 4

11. I deal with the stress of being from a family affected by 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 being from a family affected by 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 being from a family affected by 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 being from a family affected by 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:

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

18. When I am trying to sleep, I **can't stop** thinking about the stress of being from a family affected by Huntington's disease, or I have bad dreams about being from a family affected by 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 Drawing/painting
 Complaining to let off steam Being sarcastic/making fun
 Listening to music Punching a pillow
 Exercising Yelling
 Crying None of these

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:

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

22. I **just can't** get myself to face the stress of being from a family affected by Huntington's disease. 1 2 3 4

23. I wish that someone would just come and take away the stress of being from a family affected by Huntington's disease. 1 2 3 4

24. I do something to try to fix the stressful parts of being from a family affected by Huntington's disease. (remember to circle a number.) → 1 2 3 4

Write one thing you did: _____

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

WHEN DEALING WITH THE STRESS OF BEING FROM A FAMILY AFFECTED BY HUNTINGTON'S DISEASE:	How much did you do this?			
	Not at all	A little	Some	A lot
25. Thoughts about being from a family affected by Huntington's disease just pop into my head.	1	2	3	4
26. When I am dealing with the stress of being from a family affected by Huntington's disease, I feel it in my body. (<i>remember to circle a number.</i>) →	1	2	3	4
Check all that happen:				
My heart races <input type="checkbox"/>	My breathing speeds up <input type="checkbox"/>	None of these <input type="checkbox"/>		
I feel hot or sweaty <input type="checkbox"/>	My muscles get tight <input type="checkbox"/>			
27. I try to stay away from people and things that make me feel upset or remind me of being from a family affected by Huntington's disease.	1	2	3	4
28. I don't feel like myself when I am dealing with the stress of being from a family affected by 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 being from a family affected by Huntington's disease or how I'm feeling.	1	2	3	4
31. When the stressful parts of being from a family affected by 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. (<i>remember to circle a number.</i>) →	1	2	3	4
Check all you went 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
33. When the stressful parts of being from a family affected by Huntington's disease happen, I can't always control what I do. (<i>remember to circle a number.</i>) →	1	2	3	4
Check all that happen:				
I can't stop eating <input type="checkbox"/>	I can't stop talking <input type="checkbox"/>			
I do dangerous things <input type="checkbox"/>	I have to keep fixing/checking things <input type="checkbox"/>			
None of these <input type="checkbox"/>				
34. I tell myself that things could be worse.	1	2	3	4
35. My mind just goes blank when the stressful parts of being from a family affected by 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 being from a family affected by Huntington's disease, right away I feel really: (<i>remember to circle a number.</i>) →	1	2	3	4
(Check all you feel.)				
Angry <input type="checkbox"/>	Sad <input type="checkbox"/>	Scared <input type="checkbox"/>	Worried/anxious <input type="checkbox"/>	
			None of these <input type="checkbox"/>	
38. It's really hard for me to concentrate or pay attention when the stressful parts of being from a family affected by Huntington's disease happen.	1	2	3	4
39. I think about the things I'm learning from being from a family affected by Huntington's disease, or something good that will come from it.	1	2	3	4
40. After something stressful about being from a family affected by Huntington's disease happens, I can't stop thinking about what I did or said.	1	2	3	4

WHEN DEALING WITH THE STRESS OF BEING FROM A FAMILY AFFECTED BY HUNTINGTON'S DISEASE:	How much did you do this?			
	Not at all	A little	Some	A lot
41. When stressful parts of being from a family affected by Huntington's disease happen, I say to myself, "This isn't real."	1	2	3	4
42. When I'm dealing with the stressful parts of being from a family affected by 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 being from a family affected by Huntington's disease by: <i>(remember to circle a number.)</i> →	1	2	3	4
Check all that you do:				
Exercising <input type="checkbox"/> Seeing friends <input type="checkbox"/> Watching TV <input type="checkbox"/> None of these <input type="checkbox"/>				
Playing video games <input type="checkbox"/> Doing a hobby <input type="checkbox"/> Listening to music <input type="checkbox"/>				
44. When the stressful parts of being from a family affected by 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 being from a family affected by Huntington's disease. <i>(remember to circle a number.)</i> →	1	2	3	4
Check all that you do:				
Take deep breaths <input type="checkbox"/> Pray <input type="checkbox"/> Walk <input type="checkbox"/>				
Listen to music <input type="checkbox"/> Take a break <input type="checkbox"/> Meditate <input type="checkbox"/> None of these <input type="checkbox"/>				
46. I just freeze when I am dealing with stressful parts of being from a family affected by Huntington's disease, I can't do anything.	1	2	3	4
47. When the stressful parts of being from a family affected by 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 being from a family affected by 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 being from a family affected by 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 being from a family affected by 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 being from a family affected by 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 being from a family affected by Huntington's disease, sometimes I can't control what I do or say.	1	2	3	4