

ID: _____

Date: _____

RESPONSES TO STRESS – [SC] (SR-P)

This is a list of things that parents of children with sickle cell disease 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. Not knowing if my child’s sickle cell disease will get better	1	2	3	4
b. The effects of my child’s sickle cell treatment - how it changes the way he/she looks and behaves, how much it hurts or makes my child feel sick	1	2	3	4
c. Talking with my child about sickle cell disease	1	2	3	4
d. Not being able to help my child feel better	1	2	3	4
e. Arguing with my child about taking medicines and other treatments	1	2	3	4
f. Understanding information about sickle cell and medical treatments	1	2	3	4
g. Talking to my other children, family and friends about sickle cell	1	2	3	4
h. Having less time and energy for my other children and/or spouse/partner	1	2	3	4
i. Needing more help and support from family and friends	1	2	3	4
j. Paying bills and family expenses	1	2	3	4
k. Concerns about my job or my spouse/partner’s job	1	2	3	4
l. 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 something stressful happens. Everyone deals with problems in their own way – some people do a lot of the things on this list or have a bunch of feelings, other people just do or think a few of these things.

Think of all the stressful parts of having a child with sickle cell disease that you indicated 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 have the problems with having a child with sickle cell like the ones you indicated above. Please let us know about everything you do, think, and feel, even if you don’t think it helps make things better.

	How much do you do this?			
WHEN DEALING WITH THE STRESS OF HAVING A CHILD WITH SICKLE CELL: little	Some	Not at all A lot	A	A
1. I try not to feel anything.	1	2	3	4
2. When dealing with the stress of having a child with sickle cell, I feel sick to my stomach or get headaches.	1	2	3	4
3. I try to think of different ways to change or fix the situation. Write one plan you thought of: _____ _____	1	2	3	4
4. When faced with the stress of having a child with sickle cell, I don’t feel anything at all, it’s like I have no feelings.	1	2	3	4

WHEN DEALING WITH THE STRESS OF HAVING A CHILD WITH SICKLE CELL: little	How much do you do this?			
	Some	Not at all A lot	A	
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 child's sickle cell 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>) → 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	1	2	3	4
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 child's sickle cell does not exist.	1	2	3	4
10. I just have to get away from everything when I am dealing with the stress of having a child with sickle cell.	1	2	3	4
11. I deal with the stress of having a child with sickle cell 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 a child with sickle cell.	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 a child with sickle cell, 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 a child with sickle cell, 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. (<i>remember to circle a number.</i>) → 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	1	2	3	4
18. When I am trying to sleep, I can't stop thinking about the stressful aspects of having a child with sickle cell or I have bad dreams about my child's sickle cell.	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. (<i>remember to circle a number.</i>) → I do this by: (Check all that you did.) <input type="checkbox"/> 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	1	2	3	4
21. I get help from other people or things when I'm trying to figure out how to deal with my feelings. (<i>remember to circle a number.</i>) → Check all that 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	1	2	3	4
22. I just can't get myself to face the stress of having a child with sickle cell.	1	2	3	4

You're half done. Before you keep working, look back at the first page so you remember the aspects of having a child with sickle cell that have been stressful for you lately. Remember to answer the questions below thinking about these things.

WHEN DEALING WITH THE STRESS OF HAVING A CHILD WITH SICKLE CELL: little	How much do you do this?			
	Some	Not at all A lot	A	
23. I wish that someone would just come and take away the stressful aspects of having a child with sickle cell.	1	2	3	4
24. I do something to try to fix the stressful aspects of having a child with sickle cell. Write one thing you did: _____ _____	1	2	3	4
25. Thoughts about the stressful aspects of having a child with sickle cell just pop into my head.	1	2	3	4
26. When I am dealing with the stress of having a child with sickle cell, I feel it in my body. (remember to circle a number.) → Check all that happen: <input type="checkbox"/> 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	1	2	3	4
27. I try to stay away from people and things that make me feel upset or remind me of the stressful aspects of having a child with sickle cell.	1	2	3	4
28. I don't feel like myself when I am dealing with the stress of having a child with sickle cell, 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 stressful aspects of having a child with sickle cell or how I'm feeling .	1	2	3	4
31. When something stressful happens related to my child having sickle cell, 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.) → 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	1	2	3	4
33. When something stressful happens related to my child having sickle cell, I can't always control what I do. (remember to circle a number.) → Check all that happen: <input type="checkbox"/> 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	1	2	3	4
34. I tell myself that things could be worse.	1	2	3	4
35. My mind just goes blank when something stressful happens related to my child having sickle cell, 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 am faced with the stressful parts of having a child with sickle cell, right away I feel really: (remember to circle a number.) → Check all that you feel: <input type="checkbox"/> Angry <input type="checkbox"/> Sad <input type="checkbox"/> None of these <input type="checkbox"/> Worried/anxious <input type="checkbox"/> Scared	1	2	3	4
38. It's really hard for me to concentrate or pay attention when something stressful happens related to my child having sickle cell.	1	2	3	4

WHEN DEALING WITH THE STRESS OF HAVING A CHILD WITH SICKLE CELL: little	How much do you do this?			
	Some	Not at all A lot	A	
39. I think about the things I'm learning from having a child with sickle cell, or something good that will come from it.	1	2	3	4
40. After something stressful happens related to my child having sickle cell, I can't stop thinking about what I did or said.	1	2	3	4
41. When stressful parts of having a child with sickle cell happen, I say to myself, "This isn't real."	1	2	3	4
42. When I'm dealing with the stressful parts of having a child with sickle cell, I end up just lying around or sleeping a lot.	1	2	3	4
43. I keep my mind off stressful parts of having a child with sickle cell by: (remember to circle a number.) → Check all that you do: <input type="checkbox"/> Exercising <input type="checkbox"/> Shopping <input type="checkbox"/> Watching TV <input type="checkbox"/> Reading <input type="checkbox"/> Doing a hobby <input type="checkbox"/> Listening to music <input type="checkbox"/> None of these	1	2	3	4
44. When something stressful happens related to my child having sickle cell, 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 a child with sickle cell. (remember to circle a number.) → Check all that you do: <input type="checkbox"/> 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	1	2	3	4
46. I just freeze when I am dealing with stressful parts of having a child with sickle cell, I can't do anything.	1	2	3	4
47. When stressful things happen related to my child having sickle cell I sometimes 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 something stressful happens related to my child having sickle cell, 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 something stressful happens related to my child having sickle cell, I can't stop thinking about why this is happening.	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 a child with sickle cell.	1	2	3	4
54. I imagine something really fun or exciting happening in my life.	1	2	3	4
55. When something stressful happens related to having a child with sickle cell, 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

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WHEN DEALING WITH THE STRESS OF HAVING A CHILD WITH SICKLE CELL: little	How much do you do this?			
	Some	Not at all A lot	3	A 4
57. When I am dealing with the stress of having a child with sickle cell, sometimes I can't control what I do or say.	1	2	3	4