

## EMOTIONAL EFFECTS OF A SERIOUS CHILDHOOD ILLNESS

The experience of having had and survived a serious childhood illness can influence your child's emotional makeup. For some survivors, having endured and survived is a major part of their identity which can leave room for little else. For other survivors, it has little impact. This latter group likely includes children who were babies or toddlers when they were first diagnosed. In this case, your child likely has little conscious memory of the experience of treatment, although he may have some body and unconscious memories that may cause him to have reactions that surprise him or you at different moments. The impact for your very young child may be influenced by the presence or absence of chronic or late effects and on how you treat your child later. A child who remembers little and has few effects is not so likely to view his illness as a major part of his or her identity— unless it makes you extremely protective.

For your child who gets sick once conscious memories are forming, the experience can be powerful. It can take over your child's life and perhaps your family's life, too. One or two years of your child or adolescent's life may be focused on hospitals, doctors, feeling sick, getting treatment, and enduring medical procedures and appointments. Your child may miss friends, peer activities, and the developmental milestones children of his age are going through. How a young adult integrates these medical experiences with the other priorities in life can be an important task over many years before the illness is placed in a balanced perspective. Talking with a therapist who is able to listen and help your child understand his reactions in light of those experiences can be very useful.

In general, a majority of pediatric cancer survivors rate themselves as similarly or more positively psychologically adjusted compared with siblings and the general population. This is true even if they report some adverse health effects. Other challenging childhood conditions can produce similar reactions. The next two sections describe some of the more obvious positive and negative emotional effects that can occur for a child who has survived a major health problem.

### POSITIVE EMOTIONAL EFFECTS

"I've learned not to sweat the small stuff."

"It gives you a sense of perspective."

"I felt more mature than my peers after what I went through."

"I sometimes think of the paths I might have taken, but the illness also teaches you how to survive."

A child may experience several types of positive emotional effects:

- He may have developed useful ways to cope.
- He may become very motivated and determined to succeed.
- He may even know the area in which he wants to make his mark (often related to health or the health care field).
- He may appreciate his own personal strengths.
- He may be more mature and have a wider perspective on life than his peers.

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- He may be able to find meaning in negative events and to see the positive side of challenges.
- He may have better relationships and be more aware of the value of turning to others for help.

Your child has survived a challenging and life-threatening illness. He or she has probably had to endure unpleasant and uncomfortable treatments and hospitalizations in the process. He or she may have learned special skills to help cope with pain or anxiety that can be used in difficult situations in later life. A marvelous video titled *No Fears, No Tears: 13 Years Later* showed how some children continued to use the coping skills they learned during cancer treatment in useful ways afterward. Your child may have received much positive attention for what she had to go through, not only from her family but also from society in general. She has been treated in special ways. She may have attended popular baseball events, gone on trips especially for children with her condition, or been visited by athletic stars. She may have observed how other people got together to help her and her family. She may have been able to choose a wish for herself and her family. The outside world may regard her as a hero for overcoming her condition; even her friends may regard her as rather special. She may have come to believe she went through what she did for a purpose. (You may wonder the same thing.) She may be more mature than her peers and have a wider perspective on problems. She may have come to appreciate the value of life and good health and may be determined to make the most of the opportunities she now has, even if the opportunities have been limited by the illness, the treatment, and its consequences. If another adverse event happens she may be able to tell herself, "I got through my illness, I can certainly get through this."

#### **NEGATIVE EMOTIONAL EFFECTS**

There are also potentially negative emotional effects that can be associated with having been very ill as a child. First, some of the positive emotional effects can be double-edged swords. The increased maturity and changed priorities a survivor may experience may also lead to her feeling somewhat different and isolated from her peers. A survivor may justifiably feel her peers' concerns are trivial in comparison to what she has faced, and this can affect the quality of the relationships she forms. Second, there also may be mixtures of attitudes, abilities, and styles that can interact in problematic ways with being a childhood survivor. Imagine a child who has gone through a difficult treatment and is now a survivor. She has become used to others taking care of her, looking out for her, paying close attention to how she is feeling. She has been given special treatment—rules at home and in the hospital may have been relaxed for her. She has been the center of attention in her family. She may have had a tutor at home. She has experienced some of those unique privileges as well as the hardships that often go along with a challenging treatment. Maybe she already had a difficult time making friends. Maybe she is a child who found it harder than most to give up being treated specially. (And maybe her parents found it harder than most to worry less and to return to normal expectations about her behavior.) Indeed, she may have somewhat resented returning to normal life. Now let's imagine she has been back in school for a while and is finding it increasingly difficult to do the schoolwork. She finds it hard to take initiative, to organize her homework, to concentrate, or to focus on academic strategies that could help. Part of her feels it is not fair that she had been sick and does not think she should have to make any special effort to succeed academically. She may blame her difficulties on her illness. If other people find it easier to do things than she does, why should they not do them for her?

In other words, her learning difficulties are interacting with her feelings of specialness. She is noticing that others are doing better than she is, but she has a hard time taking any action that could help. She becomes a little bitter. She may begin to experience some continuing health effects that may leave her

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easily tired with less energy than her peers. She begins to worry about her future health. These worries reinforce her sense of hopelessness and helplessness. She could easily become depressed, particularly should new stressors occur.

There are some ways you can interrupt this cycle. While you are reinstating prior expectations of behavior, you can tell your sick child that you will have higher expectations for her behavior now. But you can also tell her you are so glad that she is well enough to be able to meet these expectations and you are looking forward to doing some of the things you could not do with her while she was sick. In other words, you will be emphasizing the positive side of wellness as well as the challenges that come with getting better. If she seems less motivated in school, consider whether she could have learning effects from treatment. If so, arrange a neuropsychological assessment. If she is highly unlikely to have these effects, consider what else could be going on. You can talk with her teacher and discuss ways to increase her motivation, such as focusing on a special interest at home and in school. If she has continuing health issues and seems worried about her health, warn her doctor so these concerns can be discussed when you next meet. If your child's daily functioning seems to be suffering, consider meeting with a therapist who is experienced in survivorship issues.