

The Children's Collective Document

We have not always found it easy having cancer. This has caused lots of storms for us. Many of the storms produce stormy feelings.

Feelings

As children with cancer, some of us were too embarrassed to visit with our friends or tell them we had cancer. We feared ridicule because we would lose our hair and our bodies would change because steroids often make us gain weight and our faces get round. We thought we might be less likeable and we saw that the chemotherapy and other things often made us feel angry, get angry, feel sad, and act sad, and there were lots of changes in our emotions. Sometimes we were very afraid and saddened by what we were going through so that we didn't want to face our friends who were sometimes frightened and sad too. Sometimes we noticed that our family members were frightened and sad too and this made us more fearful. Sometimes we were angry and would find it unfair.

These things were often hard to bear but we often talk to family members. We call this coping trick; family.

Family

Many of us found it helpful to talk to family members about the worries, fears, angers, embarrassment and sadness.

“I did not want those in my school to know that I had cancer and then my older brother came home from school one day and I overheard him tell my parents that they had been lying to him. One of his classmates had come to him and said, ‘I heard your sister has only a month to live.’ I was really frightened then, because I thought my parents were lying to me too. But my mom noticed I was listening and she got us all together to talk about my cancer. She told me my cancer was the best of a worst thing that can happen to someone. That she had been told by the doctors that the chemotherapy would kill the cancer cells and our life together as a family would go on. I felt better. But I still felt the anger because people at school knew what was happening to me.”

Sometimes guilt entered our lives and we wondered what we had done to deserve this.

“I used to have temper tantrums. One night I dreamed that I would get cancer. Then I did. I thought that I caused this. I told my dad. He helped me see that my tempers and my dreams could not cause cancer. He actually said, maybe this experience would help me understand better other kids because I always planned to be a teacher. I was really thankful to have my dad to talk to.”

There seems almost always to be some family member with whom we can talk.

We have sometimes worried about all these feelings but we also have found ways to overcome these feelings by talking to others. We called this coping trick, 'Others Who Understand'.

Others Who Understand

We think that it is important to have a chance to talk about our experiences and we are glad that our parents asked to have the COURAGE Group. We can talk to other kids who understand and other parents too.

COURAGE means using Cancer as an Oppportunity to Unite and share Resources in an Amicable Group setting that provides Encouragement. Our parents worked out that name. Some of these words are big but we know what courage is and we can just think of it as a *Find Bravery Group*. Talking to others who understand helps us Find Bravery.

'I find that talking to the others who come to the courage group really helps me. I like drawing and making things also helps.'

'I really got upset when the doctor told me I would gain weight and lose my hair with the chemotherapy. I love my parents but I really could not talk to them. I stopped eating and started obsessing about calories and such. Then my parents went to see a psychologist and found another one for me to talk to and that really helped me'.

Sometimes we need to talk with someone who is not in our family. Maybe that is other kids with cancer and maybe it is our friends, maybe a relative and maybe it is a professional.

Some of us find it hard to talk about cancer and about the worries but we can still get help from other things. We read, we take our values from songs, books, and movies. We call this coping trick, 'Using What We Have Around Us to Find Inspiration and Values

Using What We Have Around Us to Find Inspiration and Values.

Using things that we have read or seen has helped us find inspiration and values. This comes from such things as music, poetry, movies or books.

'I read Japanese Mangas. They often have stories of really strong women in them. There was one girl named Shinca, whose mother had died and she had to live with her grandfather whom she did not know. She was having a harder time than I am having and she could be strong. Her mother had taught her lots of values, like don't waste food and appreciate what you have. She helps me to appreciate what I have'.

'I love music and I find that there are so many hopeful lyrics, I love to sing and singing hopeful songs help me. One song by the Cowboy Fringant group is called, Holding Your Head High. It is about a boy with cancer who went to a concert the the Cowboy Fringant

Group invited him up on stage. They later wrote a song about him. Such songs help me feel less ashamed and maybe even a bit proud when I go out.'

Using things around us like music and books can give us inspiration and help us find our values.

Some of us have been brought up in certain religions and this gives us hope and help. We call this coping trick, 'Beliefs'.

Beliefs

Remembering that we have beliefs can give some of us strength.

"I have been brought up as a Hindu. When I first got out of hospital we went into a store of a friend of my mother's. This woman did not know I had cancer because we decided that we would only tell people we were sure would give us positive energy. This woman said to my mother, 'I do not know what happened to you but I can tell you are suffering'. She told my mother that she participated in a meditation group and she suggested that my mother try it. My mother thought about it and in a few weeks she went, and then she persuaded my dad and me to come. The meditation is really helping me find peace, even in a time of trouble".

"My great aunt brought back holy water from France. Every day my mom gives me a sip and we pray before going for my chemotherapy. Something about that really gives me hope."

Beliefs can give some of us strength and hope.

Some of us can no longer participate in the sports that really helped us before now. We do not have the energy and we cannot go into crowds or groups of people. But there are lots of things to learn about sports and some of us learn values from sports. We call this coping trick: 'What we can learn from sports'.

What we can learn from sports.

"I used to play soccer and now I can't. I love soccer. I can always think about when I will play again. I can watch soccer too. They work in good team work and if they don't play as a good team then they won't win any games. I have to be part of a different team now, the hematology/oncology team. This team includes me, my family and all the medical people. We are all working together for my cure and the cure of my friends. Knowing about teamwork helps me work better with this team."

Some of us get help from sports. We can learn to cope from so many different things and for some of us thinking of sports helps.

Some of us felt that the experience of having cancer has taught us a lot. We called this coping trick: What we can learn from having cancer.

What we can learn from having cancer.

“I decided that health and my body are very important. I now think about how I can take care of myself. I think of the foods I eat and what I put into my body. I’m not sure I would have learned this without the experience of being ill”.

“I learned to not let the little pains bother me. I now know the difference between big pain and little pain.”

“I learned to appreciate school more and how to be useful to others. When sitting in the hospital I felt useless and missed the learning from school. Now I think of how to be useful and how to appreciate”.

Some of us have learned a lot because we were sick.

We all have been suffering a lot but we found that we also have lots of coping tricks. We talk to family, we talk to others who understand, we can use what we have around us like music, books or movies and we can use our religion and sports and we realized that the experience taught us a lot. All these things can help us keep strong.

From a presentation given by Linda Moxley
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