

Helping Children and Teens during Difficult times



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The Purpose of this Guidebook

“Many parents and caregivers hesitate over giving information to children and teens when someone in their family receives a diagnosis of a life-threatening disease because they do not want them to worry, they believe children won’t understand, or they are not comfortable talking about such a difficult subject. Parents and caregivers may feel so shocked and overwhelmed by the news that they aren’t able to talk about it.

Whatever children are told, they will be hugely affected by the diagnosis and what lies ahead. They will see side effects of treatments and the changes in family roles and activities. They will hear conversations about the illness. They will be aware of the stress, grief, fear, and powerlessness of the adults in their lives.

It is important that children feel included and informed about what is happening in their family. Sometimes, parents do not realize how much information their children have gathered, or how accurate it is. Children will rely on their imagination or past experiences; including television programs, movies, or friend’s stories, to fill in missing details. Support and appropriate information are crucial to how children will deal with diagnosis, recurrence, and chronic illness. “ (Victoria Hospice Society, Cairnes, Thompson, Wainright, 2003).

This guidebook is intended to help parents and caregivers talk to and support their children during this difficult time, focusing on ways to talk to children about their loved one’s sickness and help children express their feelings in age-appropriate ways.

Talking to your Children about the Illness

“Children and teen’s reactions to diagnosis and recurrence will reflect the reactions of the adults around them. They will also be influenced by the information they are given and their level of understanding about the significance of the diagnosis or recurrence.

Children and teens will likely be more affected by what is happening in their daily lives than by what is anticipated or feared in the future. Changing routines and responsibilities, family stress, and the side effects of treatments experienced by their loved one may disrupt their personal world in ways that create a sense of loss and chaos that needs to be addressed.

Children and teens are better able to understand and integrate the meaning of life-threatening illness when they are included in illness-related discussions and activities, encouraged to ask questions, and given information in age-appropriate language and manageable amounts... Things that are known and familiar tend to be less confusing and frightening. Children need to have a balance between being involved with their ill family member’s life and maintaining their usual activities and normal childhood experiences. ” (Victoria Hospice Society, Cairnes, Thompson, & Wainright, 2003).

Some key points (Victoria Hospice Society, Cairnes, Thompson, & Wainright, 2003):

- Children’s and teens’ reactions to someone who is seriously ill are highly influenced by the reactions of significant adult role models (e.g., parents, grandparents, teachers, coaches).
- Children and teens may fare better if they are included with the family through this time. For this to happen, they need clear and ongoing information, adequate preparation, and appropriate support.

Here are a couple of suggestions for helping you talk to your children and/or teens about the illness:

- Find out what your children believe about the cause, treatments, and expected progression of the illness.
- Ask your children how this illness is affecting their lives and whether they have any solutions in mind.
- Find out how comfortable your children are with the way the adults in your family are expressing their thoughts and feelings. Ask about their personal thoughts and feelings (e.g. *“Jill, I know that dad was crying earlier. How was that for you?”* or *“What are you feeling about mom’s illness and how things are going?”*)
- Ask your children or teen if they want to be included in discussions or activities (e.g. *“Timmy, would you like to visit your grandma? Is there anything you want to know before you do? What do you think she will look like?”* Or, *“Chelsea would you like to write a note, draw a picture, or give me something to take to your dad when I see him today?”*)

How Children Express Themselves When Someone They Love has a Life-Threatening Illness

‘The ways in which children and teens express themselves will change as they grow and develop. Young children (2-5 years) tend to express themselves sporadically- in intense, brief bursts of feelings- and then move on to happier activities. In middle childhood (6-11years), children often express their feelings physically through their behaviours. Early teens often withdraw and internalize their pain. By the time children are in their later teens, the expression of feelings will be quite similar to adults.

Thus children and teens will express themselves in ways that reflect their developmental understanding and will change with each new developmental stage. Young children have a very egocentric view of the world and need help to understand that the illness is not their fault. Older children often worry about their own health and vulnerability and need reassurances about their own health and the health of their parents and others. Young teens, separating from parents and establishing themselves with peers, need guidance to prevent them engaging in acts of rebellion, such as skipping school, vandalism, or theft. Older teens must continue to envision themselves outside the family and plan for their independent future.

Children and teens need opportunities to talk openly about the illness and feel heard, and also not pressured to talk when they don’t want to. They need to have permission to ask questions, and to share feelings. They look to adults to learn what to expect and how to deal with all the troubling thoughts and feelings that may surface.

Children and teens may be full of overwhelming emotions, particularly fear, guilt, anger, and sadness. Often, children and teens will express these feelings through behaviours, which can make them seem unmanageable and demanding, displaying more sulking, clinging, or misbehaving than usual. These challenging behaviours make it difficult for parents, in the midst of their own feelings, to support their children and develop or

maintain ways of fostering order and respect in the family. Support from other adults who play a key role in the children's lives can be crucial. It is important for the teachers to know about the illness in the family so they can acknowledge the situation, and provide assistance with schoolwork. Supportive adults can offer the child some protection from the ignorance or discomfort of their peers and help friends understand how to be helpful' (Victoria Hospice Society, Cairnes, Thompson, & Wainright, 2003).

A child's world is primarily a world of play and spontaneous creative expression

- Children will teach you more through their behaviours/actions than through their words.
- By engaging children in the creative process, we can encourage them to externalize their inner worlds, and begin the process of integration needed to overcome the fragmentation an illness in the family can bring.
- The arts provide children with an outlet for the safe expression of feelings. In the pounding of a drum, the creation of their own personal, improvised music, in scribbling colours on a page, or painting a picture, children can release some of the strong, intense feelings they are experiencing (Mohan Van Heerden, 2003).

When Art Speaks Louder than Words:

"Sometimes, it also seems that children simply know "more than they can say" ... and this is often evident in their artwork. Children's capacity for creativity draws them naturally to the arts as a "language" which allows them to express symbolically and metaphorically their inner worlds. If we cannot speak of, or express our suffering (and this includes the nonverbal possibilities of expression), we may be destroyed by it, or immobilized by apathy" (Mohan Van Heerden, 2003).

When Your Child Is Angry

Like adults, children get angry sometimes. They may not get angry about the same things we do, and the things that anger them may sometimes seem insignificant to us, but their anger is just as real as ours.

It's important to listen to and affirm children's anger. Don't dispute or discount their experiences or feelings. It's vital to children's self-esteem that their feelings be accepted unconditionally, without debate. If a child feels angry, there is a reason, even if we as adults may not be able to see it or agree with it. To deny a child's anger or make light of it is a mistake. Children may learn from this that they can't trust themselves or their feelings, and they may come to think that their feelings don't matter.

The best way to affirm and acknowledge your child's anger is simply to reflect back the information that the child gives you.

Instead of saying:

- "What are you getting so upset about?"
- "It's not that bad!"
- "Good girls/boys don't get angry."
- "You shouldn't feel that way."
- "You shouldn't say that."
- "It's not nice to get angry."
- "You have nothing to be angry about."
- "Maybe Santa Claus is watching and you won't get any toys for Christmas!"
- "You don't know what real problems are."
- "I hate you too!"

Try saying:

- "I'm glad you can tell me how you feel."
- "You are really angry right now!"
- "Everyone gets angry sometimes."
- "Anger is part of living."

- “You are feeling very frustrated.”
- “Wow! You sure are angry.”
- “That happens sometimes.”
- “You’re allowed to feel angry but it’s not okay to behave that way.”
- “Where do you feel your anger in your body?”

Often this is all children need to work through and even get over their anger- a caring adult who takes the time to listen and say, “I understand how you feel and it’s okay” (Murphy Payne & Rohling, 1994).

When Your Child Is Sad

“Children have many complex emotions, including sadness. It’s important for children to know that it’s okay for them to feel sad and that everyone feels sad sometimes.

Encourage your child to talk about his or her sad feelings, if he or she wants to talk. Some children will show their sadness but won’t want to talk about it or won’t know how to talk about it. Sometimes they won’t even know why they are feeling sad, just that they are.

The best way to affirm and acknowledge your child’s sadness is simply to reflect back the feeling messages your child gives you.

Instead of saying:

- “That’s nothing to cry about!”
- “Stop that crying or I’ll give you something to cry about!”
- “You don’t know what real sadness is!”
- “You’ve got nothing to be sad about/to cry about.”
- “Your crying is making me sad.”
- “Be a good girl/boy and stop crying.”
- “Don’t cry.”
- “Big boys don’t cry.”
- “Be brave.”

Try saying:

- “You’re feeling really sad right now.”
- “You look very sad.”
- “It’s okay to cry.”
- “It’s all right, go ahead and get it out.”
- “I know how sadness feels.”
- “It’s important to listen to your sadness.”
- “Where do you feel your sadness in your body?”
- “I get sad too sometimes.”

Often this is all children need to start working through their sadness-someone who empathizes and says, “You’re not alone” (Murphy Payne & Rohling, 1994).

When Your Child Is Afraid/Worried

“It seems that some children aren’t afraid of anything while others are afraid of everything. It’s easy to get impatient with a child who seems excessively afraid or worried. Children face a world that is full of uncertainties and frightening things, both imaginary and real.

It’s important to validate every experience your child has with fear, even if you don’t share those fears. Encourage your child to talk about his or her fears, if he or she wants to talk.

The best way to affirm and acknowledge your child’s fears is simply to reflect back the feeling messages your child gives you.

Instead of saying:

- “That’s nothing to be scared of/worried about.”
- “What are you making such a big deal for?”
- “Act your age!”
- “Grow up!”
- “Don’t be such a scaredy-cat!”
- “Don’t worry!”
- “There’s nothing to be afraid of.”

Try saying:

- “That’s really scary!”
- “I’m glad you can tell me what scares/worries you.”
- “That can feel scary sometimes.”
- “Everybody gets scared/worried.”
- “It’s okay to be scared.”
- “I get scared/worried sometimes.”

Often all children need is to know that someone bigger who loves them understands and respects their fears. This can give them the courage to face their fears and eventually overcome them” (Murphy Payne & Rohling, 1994).

Children’s Activities for Expressing Emotions

Scream Box

Equipment: Cereal box, paper towel tube, tape, paper, scissors.

1. Stuff a cereal box with crumpled paper.
2. Close the cereal box and cut a hole in the top for the paper towel tube.
3. Tape the paper towel tube to the hole in the cereal box.
4. Decorate the box however you want.
5. Scream into the box!!!

Mad Box

Equipment: Box of any size, tape, paper.

1. Fill the box with paper, you can cut pictures from a magazine or write down things that make you mad.
2. Tape the box shut.
3. Use a plastic bat, or jump on the box until it’s in shreds.
4. Burn or recycle the remnants!

Worry Beads

Equipment: Sculpy clay, toothpick, old cookie sheet.

1. Create beads from clay; use a toothpick to put a hole in the middle.
2. String the beads after baking in the oven according to package directions.

Clay Sculpting

Equipment: Clay or playdough, water for softening clay.

1. Use the clay to mold into different shapes.
2. The feel of the clay can be soothing, anger can be released when children throw it onto a hard surface.

Getting at Guilt

Equipment: Small, safe space, telephone books.

1. Sit with the child or children in a circle and talk openly about how you have experienced guilt feelings when someone they love got sick.
2. Ask if the children have had feelings like that and then have each person say "it's not your fault" to the person next to them.
3. Tear up the phone books while saying "its not my fault!" letting the momentum build as you tear up more books!
4. Cool down by stuffing the paper (your guilt) into trash bags or by sitting in a quiet place, discussing the children's feelings.

Some more activities for helping children through a crisis:

- Setting up building blocks and knocking them down
- Pillow fights
- Fill a plastic bag with plastic bottles and let the children kick the bottles, find a safe place to go and throw stones.

'MY FEELINGS MAP' ACTIVITY

Finding a path through our feelings when someone we love is very sick is hard work. It takes lots of time, a good support system and lots of energy ...

Can you create a map that shows where you are on your own path through your mom/dad/grandma/grandpa sickness? You can add words, pictures, stickers or just use colours that show how you feel. There is no right or wrong way to do this activity, only your way ... Everybody's map will be different because everybody has their own feelings and experiences. There can be 3 or 4 sections to your map:

#1: Before the sickness

#2: When the sickness happened ...

#3: The hard times ...

#4: Healing times ...

Here are some things to think about to get you started:

I felt _____ when mom/dad/grandma/grandpa first got sick.

I felt _____ when mom/dad/ grandma/grandpa got really sick and I knew s/he was not going to get better.

I noticed that other people in my family felt _____ when mom/dad/grandma/grandpa got sick.

The hardest thing since they got sick has been _____.

One of the things that I have learned about myself since mom/dad/grandma/grandpa got sick has been _____.

Being at school since mom/dad/grandma/grandpa has been sick

_____.

My friends have been _____.

My family has been _____.

I feel better when I _____.

Today I am feeling _____.

Things that helped me feel better are (places, people, activities, pets, etc.)

_____.

JOURNAL WRITING IDEAS

Keep your hand moving. Lose control. Be specific. Don't think. Don't worry about punctuation, spelling or grammar. Write about what's important to you ...

I'm thinking of .../ I'm not thinking of ...

I want ... / I don't want

I feel ... / I don't feel

What I really want to say is ...

The first time I saw him ...

The best time ... / The worst time ...

I wish I could go back and change ...

The hardest thing in my life right now is ...

Over this past year I have learned that I ...

Recommended Booklist

The Next Place

by Warren Hanson

When Someone You Love Has Cancer: A Guide to Help Kids Cope

by Alaric Lewis

Because . . . Someone I Love Has Cancer: Kids' Activity Book -

by American Cancer Society

When a Parent Has Cancer: A Guide to Caring for your Children

by Wendy S. Harpham

What Is Cancer Anyway?: Explaining Cancer to Children

by Karen L. Carney

Becky and the Worry Cup: A Children Book about a Parent's Cancer

by Wendy Schlessel Harpham

David and the Worry Beast: Helping Children cope with Anxiety

by Anne Marie Guanci

An Open Family Book for Parents and Children Together

by Sara Stein and Dick Fran

How Do We Tell the Children

by Dan Schaefer & Christine Lyons

Talking About Death: A Dialogue between Parent and Child

by Earl Grollman

Internet Resources

BC Council for Families- <http://www.bccf.ca/>

Youthspace- <http://youthspace.ca/>

Canadian Virtual Hospice-

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Hospice Foundation of America- <http://www.hospicefoundation.org/>

References

Victoria Hospice Society, Cairns, M., Thompson, M., & Wainwright, W. (2003). *Transitions in dying and bereavement*.

Murphy Payne, L., & Rohling, C. (1994). *A Leader's Guide to Just Because I Am*.

Mohan Van Heerden, H. (2003). *A circle of loving and creating: Journeying towards wholeness in the arts therapies with children who grieve*. (PHD Thesis Dissertation).

Thanks to Danielle Schroeder, Patient & Family Support Counsellor

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