

Parenting a Dying Child

Emotional distress

The health professionals will give you many handouts with advice on how to parent a child through the end stages of his life. Many of these will ask you to “stay calm” so that you are a support for your child and others in the family. Staying calm in the face of the stormy emotions swirling inside you, and the storms blowing up around you, is a challenge. The challenge is not one you may always be able to meet.

No one expects that you will be in control of yourself all the time. Nor can you be responsible for making all the fear, envy, anger and sadness go away for every member of your family. But these natural feelings cannot be ignored. This section is offered to you with humility. We hope you will find a few bits of wisdom that will help you respond to the emotions of distress that tear through all families facing grief of this kind.

Consider what you can draw on for your own emotional support

Parents are the centre of their child’s life. Your child will draw his strength and courage from you. How the parent responds and copes directly affects how well the child can respond and cope. From whom and from where will you draw your strength and courage?

What restores your soul?

- * Think about what has helped you through difficult times in the past – meditation, prayer, exercise, physical intimacy or group activities like singing in a choir? Give time to these things. You will pay it back to your sick child and family many times over.
- * Who are the people you can turn to for support and comfort?
There may be times when you must let go and fall apart. You may have tough feelings you need to talk through and understand. To whom can you turn? The obvious people may not always be the best. Your partner may be too tense to take on your emotions. Your mother may be more controlling than helpful when she is fearful herself. Think about who in your life, friends or advisors, you can trust to listen and not judge. Who gives you a lift? Who knows what to say and when not to speak? Ask these people for help. Reach out for them when you are in need. Hard as this may be for you, you will need them.
- * Find ways to kindly, but firmly, keep short your time with people who drain your emotional energy. You have none to spare now.
If you find that there is no-one who is able to offer enough support, or helpful support, ask a healthcare professional to suggest some counsellors who may be useful to you.

*One parent described it this way,
Sometimes I felt like I was trying to
hold back the sea tides of rage in the
morning and then make the sun
shine in the dark nights of despair! I
couldn't do it everyday...no one can.*

**Don't turn aside your feelings
and needs.**

**When you ask someone for help,
you do her great honour. She will
be thankful to have a way to be
helpful.**

Consider how you support your child through times of distress

Children who understand that they may not live to grow up can grieve this loss very deeply. Some may become depressed. These emotions are a reasonable response to the unfairness of their life now and in the future. Like adults, children experience and express their grief in different ways. Depression and grief have many masks. Watch for:

- ♦ *anger*: from irritation to rage;
- ♦ *fear*: from clinging and dependency to terror;
- ♦ *sadness*: from dullness to despair;
- ♦ *withdrawal*: from lack of interest to loss of concentration to shutting out the world;
- ♦ *helplessness (regression)*: from confusion to loss of control. (This can show itself in the loss of skills, e.g., the child who has learned bladder control goes back to wetting, or the child who has learned to control his impulses - e.g., waiting his turn - now snatches and hits);
- ♦ *guilt*: from self-blame and shame to over concern for others, especially parents.

* Be accepting of your child's hard feelings

The most important thing you can do for your child is to have the courage to see, hear and respond to the hard emotions he may have – the fear, anger and depression.

Accepting these as part of your child's being at this time allows your child to share with you. Sharing is supporting. Sharing halves the burden of grief.

* Be sensitive to the many ways children show their feelings

Some children act out feelings (temper tantrums, tearfulness). Others turn inward (withdraw, sleep, lose interest, pretend or deny feelings). Pay attention to what your child is doing. It gives clues to what your child is feeling.

* Help your child name and allow his feelings

Even if your child speaks easily and has many words, he may not be able to connect with, or express, the feeling inside. Encourage your child to express concerns. Notice your child's behaviours and comment on them: *I notice you looked nervous when I talked about the home care nurse coming today. Can you tell me what you are worried about?*

Will my child lose hope? Will she have fears that I can't fix? How do I respond to his tears and worries?

Parent voice:

There were times when I responded to my child's outbursts with outbursts of my own. I acted out my pain when he said hateful things. I had terrible guilt afterwards. I forgave him easily enough, but I had to work on forgiving myself.

Reflect the feeling behind what your child says.

You told your brother he was not nice when he left to go to his soccer game. What were you feeling? Were you feeling sad that you could not go too?

It seems like you get mad when I ask you to take your medication. .. Is that right? I wonder if your medication reminds you that you are sick. (Allow time for the child to agree or disagree.)

* **If possible find a safe way to let go of the feeling**

Work with your child to find ways to get the feelings under control.

- ◆ Provide outlets that match the feelings.

Let's draw a picture of the medication and tear it up."

Let's give the medication a gross name! What shall we call it? Would you like to make a label with the new name and then we will stick it on the bottle?

It isn't OK to hit your sister or the table with the tennis racket. I won't let you do that but you can hit your mattress with that tennis racket if it helps get rid of the bad feeling.

I'm feeling sad too; let's give each other a long, long hug.

- ◆ Use distractions like fantasy and storytelling to take your child into "another world," a happier place. Lead your child into imagining things with you, Using a quiet, relaxed tone, lead your child like this:

Remember where we camped the first night surrounded by green trees—can you picture that?

I see the hummingbird that visited, do you....?

I hear the water against the rocks...

Let's plan some adventures for our imaginary camping trip.

That night we made pancakes, what shall we make tonight...?

* **Use medication if it will help**

In the past few years, we have learned that careful use of medication can be helpful at times of great anxiety or distress. Talk with a healthcare professional about it. Our goal is always to help the child cope in order to tap into her own inner strengths.

Building stories can be a creative activity to do together. You can also do some of these as a tape-recording for your child. She can then play them at any time. She might like to record a story for you.

A word about anxiety and fear

It is normal for a child who knows he is very sick to have times when he is afraid. The greatest fear for many parents is talking to their child about death. (Refer to the section on this topic). But don't assume all the child's fears are to do with the sickness or death. All children have fears because so much of the world is unknown. The fear may be of the shadow on the ceiling or the monster under the bed.

Learn how to use a calm voice and manner to be a calm presence:

- ◆ Speak in a slow, low voice.
- ◆ Relax your body, slow and deepen your breathing.
- ◆ Slow down your movements.
- ◆ Remind your child that you are there to keep him safe.

What may help:

- ◆ Sort out with your child what is a real threat and what is not.
- ◆ Tell your child often that you will be with her to keep her safe. Tell him that he can call for you when he is afraid.
- ◆ Talk about the fears you had when you were a child and what you did about them.
- ◆ Try to offer your child some real choices when possible.

Would you like your grandma to stay with you when I go out today or shall we ask Sarah to come and be with you?

When you wake in the night and you feel afraid, do you want to come into the cot in our room, or shall I come into your room?

A word about anger:

One of the most frightening aspects of grief or depression is its anger mask. This is especially hard when the anger is turned against the parent - the one trying hardest to "makes things better." The parent is IT because the child feels safest with you. No matter how "bad" the child acts, he knows that this person will always love and care.

What may help:

Anger is just another emotion and cannot be denied. However, you cannot allow the anger to hurt anyone. If your child has no control over the impulse to hit, bite, yell or insult, you will need to set and maintain the limits. Think about this as a return to baby behaviour - a loss of a self control skill. Respond as you would to a younger child behaving in this way.

Many of the fears children have are about their lack of power and control. Your strength is their main comfort. This is why they fear less when you are calm beside them. If the parent reacts with fear, or is not present, the child feels less safe.

Choices give the child a sense of control.

Talk your child down. You might say, *I'm here for you. If it's hard for you to stop hitting and yelling, then I will help you. I will hold you gently until you feel quiet inside. I will speak softly in your ear to remind you to speak softly too. Nothing is going to get better until you are quiet inside and out.*

When you need more than parenting skills

Talk with a healthcare professional about what you are seeing. Some children will need more help getting on top of their emotional distress than good parenting. Distress storms may batter too hard at a family. These storms may leave emotional shambles. Call on the health care team for help if this is happening in your family.

End note:

So much of this is about just being with your child to hear and respond to each other as child and parent. It is not about fixing or making everything all better but being present.

As one parent said to his teenage son: *I just want you to know this one thing and remember it always – I'm on your team. Win or lose, we're going to do it together.*

This pamphlet is the result of a collaboration between
British Columbia's Children's Hospital
and
Canuck Place Children's Hospice

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BCCH-1008



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