

## **Talking to Children About Life-Threatening Illness**

When someone in the family has a life-threatening illness it can be difficult talking to children about what is happening. Many adults want to shield children from the truth in order to protect them from hurt. However, if children are not informed, they may feel isolated, alone, and not important enough to be included. If there is a serious illness in the family, children can sense anxiety and tension around them. They may often think that they have caused something bad to happen.

The information that follows offers a few guidelines that you may find helpful when talking to children. These guidelines are meant to be adapted in a manner that best suits individual family needs and communication styles.

### **When deciding to talk to children about serious illness, consider the following:**

- Put yourself in the shoes of this young person. He/she has the right to know the truth.
- Children can tell when something is wrong. They may imagine or fear the worst.
- If you do not tell the children what is happening, they may find out from someone else or overhear conversations and misinterpret the situation.
- Telling children may provide some comfort to you. You will no longer need to feel secretive.
- Coping with serious illness in the family can be a growth experience. Children can learn about feelings and the strength of the human spirit in difficult times.

### **Where to begin?**

- Talk with the child in an environment that is comfortable to them such as their room, the kitchen, the car, etc.
- Try to begin the conversation early enough in the day so that the child can have time to think about what was said and come back with questions.
- If possible, avoid talking with the child before a major event like school, a party, field trip, etc.
- Allow enough time so that you can listen without feeling rushed.
- Explain changes in routine; introduce nurses and other professionals that may be providing care in the home.

### **Helpful strategies for talking with your child:**

- Find out what the child already knows. Chances are, they already know something is wrong. Questions that are helpful to ask include: "Is there anything that has happened here in the past while that you don't understand?", "Do you know why mommy went to the hospital?", "Do you know what kind of sickness daddy has?".
- Explain the illness in simple language. You do not have to give them all the details about treatments, surgeries, etc.
- Tell them what has happened and what may happen next. If the family member is dying, do not offer false assurances to the child.
- Be open to questions and be prepared to answer them honestly.
- Tell the children how you are feeling. It is okay to show your pain and cry, children will look to you as a role model.
- Don't be afraid to say "I don't know...".
- Don't push children to talk if they are not ready.

**What Next?**

- Try to maintain the child's routine as much as possible. Let them have time to themselves (when relatives visit), continue with activities.
- Maintain discipline and rules as are normal for the family. Children need to have boundaries, and know that rules haven't changed.
- Extra hugs, kisses, and time together often go farther than words. Assure the child that they will always be supported and loved throughout this time. Let them know who will help to care for them, drive to hockey practices, etc.
- Allow the child to react in his/her own style. Some children may react immediately, while others may need some time to process the information.
- Children learn through repetition and will ask you to retell the 'story' over and over again. If this is more than you can bear, look to other family or friends who may be able to help.
- Allow time for your child to play. Children use play to work through what they have learned.

**Children can learn and grow from being around illness:**

- They can gain greater independence from being asked to help around the house.
- Children will also develop a stronger sense of responsibility.
- Children learn from watching others cope with a difficult situation.

\* Information adapted from When a Loved One is Ill by Leonard Felder, Coping With Illness by Helen Garvy, and "Helping Children Understand: A Guide for a Parent With Cancer": American Cancer Society.

## How Children Respond When a Loved One is Sick

Families coping with life-threatening illness are faced with the challenge of managing a great deal of change within the family system and outside the home. Each child's response to a loved one's serious illness will be unique. However, there are some typical behaviour changes that are typical. The following outlines some very *normal* and *common* responses children may have when a family member is ill:

### Worries:

Sometimes children will develop new fears when faced with changes within the family. Such fears might include:

- fear of hospitals, doctors, or nurses
- worry that loved ones will die and wonder who will take care of them if this happens
- wonder if they can 'catch' the family member's illness

### Helping Your Child Manage these New Worries

- Offer comfort and tell the child that these feelings are natural and won't last forever.
- Encourage children to talk about their fears aloud. This lets them know that having the worries is okay and normal.
- Have the child make up a story, song, or picture with a happy ending to the situation they fear.
- Praise your child when he/she takes a step towards taming their fear. This builds confidence.
- Take the child's fears and worries seriously. Don't laugh at, or ridicule them.

### Strong and New Feelings:

When children are told that someone in their family is ill, they will likely experience a wide range of strong emotions. Your child may feel some, or all, of the following:

- anger
- sadness
- loneliness
- guilt/responsibility
- worry
- confusion

### Helping your child manage these emotions:

- Tell them that these feelings are normal and expected.
- Explain that these emotions will get weaker or change with time.
- Explain that these feelings cannot make the sick person more sick.
- Let the child feel safe to express his/her self. Offer opportunities to talk about their feelings and ask questions.
- Encourage the child to draw things that make him/her happy, sad, mad, etc. Use these pictures as a springboard for discussion.
- Encourage non-verbal ways to release emotions/energy (sports, art, dance, play)



## **Behaviour Changes:**

When children experience stress it is common for them to show changes in their behaviour through regression or acting-out. It is important to note that when behaviour changes do occur, the child is not deliberately trying to misbehave or cause trouble. New behaviours are a sign that the child needs time to adjust to the changes at home.

### Some Behaviour Changes to Expect:

- baby talk
- thumb-sucking, bed wetting
- neglecting chores and/or homework
- playing with dolls or toys from earlier years
- refusing to dress themselves
- clinging to parent
- changes in appetite

### Suggestions for dealing with these behaviours:

- Try to bear with these behaviour changes, they will not last forever. Use the behaviour as a springboard for discussion about what the child is feeling.
- Be patient. These behaviours are only temporary while the child adjusts to stress and change.
- Provide time to talk alone with the child.
- Do not introduce new foods or eating habits. Try to keep meal times the same as they were before the family illness.

## **TROUBLES AT BEDTIME:**

Night time is often the most difficult time for families who are coping with major change. Sleep disturbances are common for children coping with change and stress as feelings of loneliness, worry, and sadness may intensify at night time.

### Some common sleep disturbances:

- bad dreams and/or nightmares
- waking in the night
- walking and/or talking in sleep
- difficulties falling asleep, crying, or refusal to go to bed alone

### Helping your child get through the night:

- Help your child 'wind-down' from their day by encouraging them to take a bath, read a story, listen to soothing music or nature sounds.
- On occasion, let the child sleep with you.
- Use night-lights in the child's bedroom and hallways or allow your child to keep a flashlight.
- Let the child sleep with his/her door open so that he/she can hear familiar sounds of voices and television.
- Encourage daily physical exercise.
- Keep the child's bedtime centred around him/her. Read stories, cuddle, tuck the child in.



## **SCHOOL ISSUES:**

Changes at home often have an impact on a child's behaviour while at school. Children coping with loss and change will often experience some of the following at school:

- troubles concentrating
- difficulties completing homework
- conflicts with peers (fighting, withdrawing)
- avoidance of school
- emotional outbursts brought on by seemingly 'minor' events

Here are some suggestions to help a child cope as best as possible while at school:

- Make sure the school knows what is going on; that there is an illness in the family.
- If the child enjoys school, assure him/her that this it is okay to have fun outside the home.
- If possible, arrange to meet with a school counsellor. Include the child in this meeting. Find out what supportive resources may be available through the school.
- Talk to the child's teacher(s). Do not assume that the counsellor will inform the teacher(s) about the situation.

\* **Information adapted from When a Parent has Cancer by Wendy Schlessel Harpham**

## **How Teens Respond to Illness in the Family**

When teens are faced with a serious illness within the family, it is sometimes difficult to predict how they will respond. Some teens will rebel, some will regress in behaviour, and others will mature rapidly. It is important to understand that teens can respond in a number of different directions, and this is okay and normal. No matter what the grief reaction, it is important to make sure that teens have someone to talk to outside the immediate family.

### **Common Responses to Serious Illness in the Family:**

- they may want a lot of information about the illness; technical terminology and statistical information on survival rates
- they will likely experience intense feelings of sadness, disappointment, anger, guilt, and/or anxiety
- they may have fall-outs with friends, or withdraw from social situations
- they may feel different from peers
- they can struggle with feelings of independence and dependence
- there may be an increase in experimentation of risky behaviours
- they may have difficulties concentrating at school

### **Tips for Parents:**

- Tell teens the facts over and over, this will help them feel more confident and secure.
- Try to continue to enforce rules and routines. Routine is reassuring.
- Establish close contact with schools. Keep teachers and school counsellors informed.
- Be sensitive to assigning new responsibilities. Do not let too much adult responsibility fall on the shoulders of teens.
- Do not make a big deal about regressive behaviours, they are only temporary while the teen adjusts to the stress.
- Protect teens from giving up too many things that interest them outside the home. Encourage teens to spend time with friends and participate in sports and other extracurricular activities.
- Find out about age-appropriate support groups.
- Make sure teens have someone to talk to (a best friend, a friend's parent, teacher, coach, Minister) outside of the immediate family.

**\* Information adapted from How to Help Children Through a Parent's Serious Illness by Kathleen McCue & When a Parent has Cancer by Wendy Schlessel Harpham**