

Helping Children When a Family Member Has a Life-Threatening Illness

Liana Lowenstein, MSW, 416-575-7836 www.lianalowenstein.com

Brianne Thompson, MSW, RSW

Talking with your child about the illness

To tell or not to tell:

Honesty helps children establish and maintain a bond of trust. The truth, even when it is painful, is vital. If a child learns of a parent's deception, they will have a problem being comforted later by words/actions wondering if the parent is telling the truth. By being truthful, you can also feel assured that the child can be guided to accurate, appropriate explanations and you can help them process their feelings and learn coping skills.

Sometimes parents are fearful of telling the child about the illness because they fear children will be overwhelmed. But if there's a delay, or if it's a family secret, the child can build up resentment. If they are not told, children as young as 3 will pick up on the tension in the home and they will feel anxious about what is really going on. Experts say that children who suspect parents of concealing something often imagine that the problem is even worse than it is because it is "too awful to be talked about." Children may also feel isolated from their parents at a time of tremendous stress.

Who should tell them?

- The parent with the illness should tell their children--if they are well enough and feel comfortable. It is OK to cry. Seeing a parent cry gives the children permission to cry also. If you feel you will be unduly upset, it might be best to have someone else tell them.
- If you cannot tell your children, then a spouse, close relative, your doctor or member of the health care team can tell them. However, it is best for you to be present with your child, as they may look to you for confirmation of this information.

When to tell them?

- Once you receive the diagnosis and treatment plan, it is best to tell them right away.
- Prior to telling your children, practice what you are going to say, as the first time that you say it out loud may be overwhelming. An option is to speak to a health care professional about how to answer potential questions.

What to tell them?

- Give your child enough information to help them understand. Provide enough facts to lessen their fears. Be as hopeful and positive as you can be.
- Name and describe the illness, i.e., "I have an illness called cancer. Cancer is bad cells that hurt the good cells in the body. The bad cancer cells make the body sick." (Try not to use words like "sickness" or "bump" instead of Cancer or tumor as this leads to more confusion.)
- Show your child what part of your body you are talking about.
- Tell them how you will be treated and any side effects they will notice, i.e., "The doctors are giving me special medicine to try to make the bad cells in my body go away. The medicine is going to help me but it will also make my hair fall out I'm going to buy a really cool looking hat to wear once my hair falls out."

- Let them know if changes will occur at home and how they will be affected because of the treatment.
- Listen to your child and his/her reactions. Answer questions truthfully. It is OK to say, "I don't know." If your child doesn't talk or ask questions, don't push them.
- Due to prevalence rates of life threatening illnesses, several children have exposure to illnesses such as cancer from family or the community. It is important to explain to children that everyone's diagnosis is different.
- Don't be afraid to share your feelings with your child, i.e., "I feel sad," "I feel angry," "I feel scared."
- Explain hospitalization. There is a chance that you may have to spend time in the hospital for treatment, and it's important for children to have a "plan". The plan should include where they will be and how they will contact you. Use of the books "The Kissing Hand" or "Invisible String" are helpful for children with separation.

Remember the 4 C's: Cause, Catch, Care, Cope:

Cause: Many children worry that they caused the illness. They may think they did something to cause the illness. They may believe the illness is a punishment for their bad behavior. Alleviate their guilt by saying, "Nothing you said or did made me get sick (or made me get cancer)."

Catch: Some children worry that they will catch your illness/cancer like they can catch a cold. Tell your child "Cancer is not contagious. You cannot get cancer from anyone else and you cannot make anyone get cancer."

Care: Children need constant reassurance that they will be taken care of. Explain to your child, "Even though I am very sick, you will still be taken care of. I have made plans for others (name these people) to help me take care of you." (Give examples, such as "Aunt Martha will be here when you get home from school and she will help you with your homework, and take you to the store to get art supplies for your project")

Cope: Children always benefit from learning healthy coping strategies. Teach your child what to do when they are feeling stressed. Say, "When you are feeling sad, scared, lonely etc. you can talk to me (or Aunt Martha, or your teacher, or). You can also draw a picture to show how you feel."

The 4C's are important to review with children at all ages. Many parents report that even their adolescent children have questioned the contagiousness of cancer.

Points to remember:

- Instead of dwelling on uncertainty, focus on the hopeful facts: "everything possible is being done, Mommy is young and strong and she is getting the best help to try to get better."
- If you never show a child your feelings, chances are they will not show theirs either. Covering up strong emotions in this instance, may not always be a good idea. A child may become frightened of his/her own feelings instead of accepting them as being OK. Don't teach your child not to be sad or angry, teach them what to do when they feel sad or angry.

- Take your children's feelings seriously. It is common for children to have many different reactions when they are told a parent has a serious illness. These can include anger, sadness, guilt, fear, confusion and even frustration. Let them know it is OK for them to have lots of different feelings.
- Sandwich the information. Start with the positive, then discuss the hard stuff, and end with the positive.
- It is very typical for children not to react after hearing information about a diagnosis. Often, children require time to process the news. A reaction can sometimes occur days afterwards. When telling your children, ensure that you review that they can talk about it, or ask questions at any time. Take the opportunity to make a support plan for your child to explain who they can talk to for help and advice.
- Speak with family members. This is very important to ensure that your child is receiving consistent information. Ensure family is aware of the terms you use with your child, and let family know when you have told your child so they can provide extra support.
- Speak with your child's school. Your child may have a reaction at school about the recent news of a diagnosis, and it's important for them to be supported. It is also normal for children to have an increase in behaviors at school.
- Maintain consistency as much as possible. It is important to keep to household rules and routines such as bedtime.

Age Differences

3-5 years

- The most stressful part of a parent's illness is the separation from the primary caregiver.
- At this age children feel they have magical powers and what they wish will come true. They may blame themselves that a parent is ill, or about having bad thoughts about that parent. They need to know that nothing they have done caused their parent's illness.
- Children in this age group do not understand the concept of death without help from adults who use clear and concise terms.

6-11 years

- Children in this age group can become overly concerned about a parent's health. Be aware so as not to worry them with details.
- Tell the children's teacher or school counselor about your condition as soon as possible.
- Changes in eating, sleeping, school work and friendships may occur.
- Children may regress in behavior. Don't punish regressive behavior such as thumbsucking, bedwetting, babytalk, etc.

Teens

- Teenagers have an especially hard time because their own emotional balance may be on a roller coaster. They may be trying to be independent, and now the parent may need to depend on them.
- Some will rebel and regress in their behavior.
- Some may tend to take on too much responsibility and mature too rapidly.
- Some will just take the experience in stride.

When the news is really hard...

Even when a parent's prognosis is really poor, it is still important to speak truthfully. If a child asks a parent if he or she is dying, a parent can answer, "I'm not dying right now. Many people with this kind of illness/cancer die, but some people get better. I'm doing everything possible to be one of the people who gets better." Parents also may want to simply explain the medical treatments they are receiving and how they may make the parent better.

How to talk to children about dying

- Children need to be prepared when a family member is dying. It is important to clearly say, "going to die." This is different and more clear than saying, "Not going to get better." Using clear language is very important. Some people have used unclear language, such as "going to sleep", which creates a fear of sleeping and you will likely see a disruption in the child's bed time routine. Terms like "gone" imply that their loved one is coming back. Use "D" words such as dying, death, dead.
- Explain what might happen with the body—that the body knows how to die
- Explain what dead means, i.e., "Soon mommy will die--her body will stop working and it will never work again. Her heart will stop beating and she will stop breathing. When she dies and her body stops working she will no longer be able to see, hear, touch, talk, or feel."
- Emphasize that medicine can still help the person be comfortable
- Prepare the child for changes at home such as health care workers coming to the home, person being moved to a hospital bed, possible emergency trips to hospital, etc.
- Involve the child in goodbye rituals, i.e. "Mommy is going to die soon. We don't know exactly when, but soon it will be time to say goodbye forever to mommy. Let's practice together first, so when we say goodbye forever to mommy you will know what you want to say." (It can be helpful to role-play saying goodbye with dolls or stuffed animals). The child may also want to make a goodbye card to give to the dying family member.
- Explain what will happen after the death and provide reassurance, i.e., "When mommy dies, she will not come back, not ever. But remember what I said earlier, I will be here to take care of you, and lots of people love you and will help take care of you."
- Even though the person is dying, emphasize they still care about the child.
- Give permission for the child to play, i.e., "Even though this is a sad time, it's okay for you to still play and have fun."

Along with honesty and reassurance, parents should watch for signs that their children are not coping well. These signals, according to experts, include a prolonged change in mood or personality, decreased appetite, withdrawal from friends and family, acting out at school or physical complaints such as headache or stomachache. Nearly all children will have some of these symptoms for a while. If it continues too long (more than 2 weeks) or interferes with daily functioning, then it's time to be concerned. Parents who are concerned with how their child is

copied should talk to the child's pediatrician, teacher, school counselor, or contact the social service department of their local hospital for referrals to social workers or counselors who specialize in helping children and families cope with illness.

Special Considerations for Siblings of Children with a Life Threatening Illness (Source: onconurse.com)

Life threatening illness touches all members of the family, with especially long-lasting effects on siblings. They often feel conflicting emotions: concern for their brother or sister, but they may also resent the turmoil within the family. They may be jealous of the gifts and attention showered on the sick child, yet feel guilty for feeling this way. They may feel alone and abandoned. They may be angry at their sibling who is sick and who can no longer play with them. They likely feel scared and worried. Below are some tips to help siblings cope:

- Bring home a picture of the sibling who is in the hospital, and carry a video recorder back and forth to relay messages
- Try to spend time alone with each sibling
- If people comment on the sick child, try to bring the conversation back to include the sibling. For example, if someone says, "Oh look how good Lisa looks," say, "Yes, and Martha has a fabulous new haircut, too. Don't you like it?"
- Discuss feelings openly, i.e., "I'm sad that I have to bring your sister to the hospital a lot. I miss you when I am gone." This allows the siblings to openly express their feelings.
- Include siblings in some appropriate decision-making. For example, ask them to help you create a family chore chart and have them decide some of the chores to include.
- Give lots of hugs, kisses, physical comfort.
- Alert teachers of siblings to the added stress that is going on at home, and ask them to be vigilant for any concerning warning signs
- The child with the illness receives toys and gifts resulting in jealousy in the siblings. Provide gifts and tokens of appreciation to the siblings for helping out during hard times, and encourage your sick child to share.
- Facilitate a close relationship between adult relatives, neighbors, close friends so the sibling has someone special to spend time with.
- Take advantage of any workshops, support groups, camps for siblings. These can provide support and positive experiences to offset the stress.

Activities for families to do together

Pillow Case

Use fabric markers to decorate a pillow case for the family member who is ill. Loving messages, favorite memories, sayings, symbols, or other meaningful images or words may be included so that the child's messages can be with her/his loved one all the time. The pillow case is then given to the ill loved one.

Three stones (Source: Winston's Wish)

Place three stones in a small bag (one smooth stone, one rough stone, and one gem stone. The first two stones can usually be found in a garden or park. Gemstones can be found at craft or gift shops.) The smooth stone is there because even though times have been hard with mum or dad's illness – ordinary everyday life still goes on. The rough stone represents the difficult and hard times. The gemstone is a reminder of the really special times together. If you have more than one child you could choose a different gemstone and different bag design for each child.

Spend time holding each stone. First hold the smooth stone. Think of some happy day to day things that have been going on at home and at school despite the illness. Now hold the rough stone. Tell about some memories or thoughts which have been rough and feel painful. Finally, hold the gemstone. Think of the special moments and times that you have shared together.

Memory Boxes (Source: Winston's Wish)

When someone is ill, a memory box can become an important way of passing on memories of treasured times to children.

What goes into a memory box? Anything you or the child wants that means something to them and has a personal story attached to it. Objects can even be labeled to prompt the kinds of stories that mean a lot to children. A photo of the child with the parent who is ill can be stuck on the lid. This provides an important reminder of their connection and leads the way into the box and the stories of its contents. All sorts of things can be collected, including tickets from places visited together, cards, feathers found on a special walk, shells from a beach holiday, certificates and anything else that has a special, personal significance. A bottle of aftershave or perfume that mum or dad uses can be included and the child encouraged to spray it on a soft toy or even themselves. Our sense of smell is one of the most powerful ways to access memories, so this can evoke strong feelings of connection with their parent when

apart. You might also write short stories or headlines for stories on a set of postcards or in a special memory book to go into the memory box.

The box can help a parent and child to have safe conversations and say things that may otherwise go unsaid for fear of upsetting each other.

Looking through the box can help with the process of grieving by bringing to mind the different aspects of the person who died – who they were, what they did or did not like, what they were good and not so good at, as well as the things that were important to them.

Collecting memories in a memory box can help children evolve a realistic sense of the person who has died, and in doing so, also help them to develop a more mature self-identity.

Pocket of Love

Often, when we are sad or having a difficult day, it is difficult to think of things that make us smile. It's a good idea to make a list of things that make us happy. Children often like to hold tangible objects that remind them of people who love them, or things that make them happy. A pocket of love is either a fabric made pocket, or a laminate pocket that can contain paper hearts. Each paper heart has a brief description of something the child likes, or people who support your child. Then the child can use the pocket as a new coping strategy to use if they have a difficult moment. The child can bring their pocket of love to school, or to a relatives home.

Toy Modification

It is important for young children to have their family's situation represented in play. If hair loss is something that is likely to occur, modifying toys could be helpful. For example, cutting the hair off of a doll to normalize hairloss to your child.

Carla Can Sing is a doll/book package that explains cancer in basic terms to children. The series includes information about a "mommy", "daddy", "grandma", "grandpa" and "sibling". (<http://www.carlacansing.com/>)

Activities for parents to do for their children

Little box of big thoughts (Source: Winston's Wish)

Writing down special memories and the thoughts you may have about the future can create a unique and special gift for your children. There are several ways to go about this. Initially it seems a daunting prospect, so don't feel you have to write everything at once. Some parents choose to write something every day; others write when they think of something they want to add.

The idea behind this activity is to write a series of cards to be kept together in a box. Index cards or small pieces of colored paper can be used. On each card write simple thoughts. Here are some starters:

I love you because

I feel proud when you

I hope that

A favourite memory I have is

You make me laugh when

When we're not together, what I miss most about you is

Remember when

Thank you for

The completed box is a unique and permanent reminder for your child that you and he/she share a secure and loving relationship – no matter what.

Letters for the future (Source: Winston's Wish)

If your illness is progressing, it's very hard to accept that you may not live long enough to see your children growing up. But although you may not be there in person, you do have a chance to write letters remembering happy times you've spent together or looking ahead to their future lives.

Some parents are put off from doing this, because they think it will be too upsetting. Others worry that messages from the past could simply re-open old wounds and cause future pain for their children.

The reality is that parents generally do find it very difficult, but also very rewarding, to write such letters. Remembering happy times and doing something positive for your children can lift your spirits and give you a sense of purpose. Although children may feel sad when they read such messages, they also say it makes them feel very loved that their parent could think ahead and do this for them.

The only real risk of letters like these is that children can feel they've been given a set of instructions which need to be followed out of respect for you. If you decide to write letters for their graduation, their marriage or the birth of their first child, it is important to emphasise that you are happy whatever path they have chosen so that they do not feel they've let you down if they don't go to university, choose not to marry or never have children.

This is the hardest letter you will ever need to write. Ideally, and if possible, personalise it to each child or write it jointly to all your children and make enough copies so they have one each.

Guidelines for writing the letter:

- Tell them in a simple and straightforward way how you feel about them. Let them know that you love them and that you would do anything not to be in this position.
- Other things that you could include might be some reflections on your life growing up and some of your struggles and successes. Help them to understand the things that have helped you cope in life and to celebrate the things you value, such as hope, perseverance and courage.
- You may want to mention the memory box that you have been gathering together.
- Also mention people, or toys which can be relied on to provide comfort.
- If you are a mother who is ill, you may want to talk about their dad, and if you are a father who is ill, you may want to talk about their mum. You may also want to talk about other key people who will cherish your children on your behalf. You may even want to mention the future possibility that your partner may find a new partner.

- Encourage them to keep their dreams, treasure their memories and share their stories with people who can hear them.

It would be good to think that the children will never have to read your letter, but if they do, it will be a priceless treasure.

About the Authors

Liana Lowenstein, MSW, RSW, CPT-S, maintains a private practice in Toronto, Canada, provides clinical supervision and consultation to mental health professionals and lectures internationally on childhood trauma and play therapy. She has authored numerous books including, Creative Interventions for Troubled Children and Youth (1999), Creative Interventions for Troubled Children and Youth (2002), Creative Interventions for Bereaved Children (2006), and Creative Interventions for Children of Divorce (2006). For more information, go to www.lianalowenstein.com

Brianne Thompson, MSW, RSW, BA, is a clinical social worker at Hospice of Windsor and Essex County, where she works primarily with children affected by a life threatening illness. She has also been working with children diagnosed with Autism for approximately ten years, both one on one support and advocacy in the community including safety initiatives. She is currently completing her certificate in Play Therapy through the Canadian Association for Child and Play Therapy.

© 2012 Liana Lowenstein and Brianne Thompson, All rights reserved.

Books for Children

When Someone Has a Very Serious Illness: Marge Heegaard

Because Someone I Love Has Cancer: Kids Activity Book (Ages 5-10)

Butterfly Kisses & Wishes on Wings: When Someone You Love Has Cancer:
McVicker

Huge Bag of Worries: Virginia Ironside

My Daddy's Cancer: An Interactive Book for Children (Ages 4-8) Cindy Klein
Cohn & John Heiney

No Matter What (Ages 3-8): Debi Gliori

Tickles Tabitha's Cancer-tankerous Mommy (Ages 4-8): Frahn

What About Me? When Brothers and Sisters Get Sick (Ages 4-8): Peterkin

Books for Parents

Extreme Parenting: Parenting Your Child with a Chronic Illness: Dempsey

Parenting Children with Health Issues: Cline

Shelter from the Storm: Caring for a Child with a Life Threatening Condition

Goldfish Went on Vacation: a Memoir of Loss (and Learning to Tell the Truth
About It): Patty Dann

How to Help Children Through a Parent's Serious Illness: McCue & Bonn

Raising an Emotionally Healthy Child When a Parent is Sick: Paula Rauch &
Anna Muriel

What is Cancer Anyway? Explaining Cancer to Children of All Ages: Carney

When a Parent has Cancer: a Guide to Caring for Your Children : Wendy
Schlessel Harpham