

When a Parent is Sick

Helping Parents Explain Serious Illness to Children

Joan Hamilton, RN, BN, MSc(A)

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Reprinted: April 2005

The author gratefully acknowledges the support of the Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia, Canada. Thanks to Gwen North for the design and layout of the previous editions.

The 1999 edition is available in French by contacting msgjeh@qe2.hsc.ns.ca

Front cover photograph by Fred Burge.

Canadian Cataloguing in Publication Data

Hamilton, Joan, 1958–

When a parent is sick: helping parents explain serious illness to children

ISBN 1-895900-40-9

1. Parent and child. 2. Critically ill – Family relationships.
3. Parents – Death – Psychological aspects. 4. Children and death.
I. Title.

R726.5.H36 2001

362.1

C2001-900027-8

Pottersfield Press gratefully acknowledges the ongoing support of the Nova Scotia Department of Tourism and Culture, Cultural Affairs Division, as well as The Canada Council for the Arts. We acknowledge the financial support of the Government of Canada through the Book Publishing Industry Development Program for our publishing activities.

Printed in Canada

Pottersfield Press

83 Leslie Road

East Lawrencetown

Nova Scotia, Canada, B2Z 1P8

Website: www.pottersfieldpress.com

To order telephone toll-free 1-800-NIMBUS9 (1-800-646-2879)



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Introduction

This book provides parents, grandparents, other family members, babysitters, and friends with some ideas and examples of how to talk to and respond to children throughout a parent's serious illness. Some of the ideas and examples have come from experts who have written books (see the selected titles in chapters 8 and 12). Other explanations and suggestions are my interpretations of what I have learned from these experts and as a registered nurse caring for cancer patients and their families. The examples in this book describe a parent who has cancer but certainly the principles or ideas apply to any type of serious illness. A mother is used in the examples to describe the parent who is sick.

At a time when so much is happening in a family's life, you may not have the time, energy and concentration to find the words to explain a diagnosis of a serious illness to your children. If you don't have the time now to read this entire book, the Quick Overview (pages 8-16) will give you the main points to consider as you talk to your children.

How children respond or react to what is happening in their lives varies a great deal. If a parent has concerns or feels that a child is having problems, that a child is struggling with things in

a way that just doesn't seem right — seek out help. If there is a children's hospital in your area, see if it has a Child and Adolescent Mental Health program. Professionals there should be able to direct you to someone. Others who may be able to assist you include someone like a school counsellor, a family doctor, a health care professional (e.g. social worker, psychologist, nurse) who is caring for the sick parent, or someone from the Cancer Society or similar organizations.

The information in this book can help families faced with serious illness in two important ways — for some it will confirm or validate that they are on the right track with how they are handling things with their children, and for others it will help guide them through unknown territory.

Joan Hamilton
March 2001

Quick overview

What should you do?

- Tell your children what is happening as soon as possible. They will sense that something is wrong. It is far better for them to hear it from you than find out another way.
- Tell all your children at the same time, even if there is an age gap. The younger ones may not understand at the level of the older ones, but they will feel included. When the children know there are no secrets, they will be better able to support each other.
- Be open and honest. Children need your trust more than ever right now. Don't risk losing it.
- Children tend to cope best when they are well informed and there are no surprises about what is happening. Keep children up to date.
- You may want to practice or write down what and how to say things. This may not be your usual way to talk with your children, but explain that what you have to say is

really important and you want to make sure you explain it correctly.

- Let other people caring for the children know how you have explained things and give them some direction on how to respond to children's questions, fears and behaviours. Some parents write down explanations or answers to questions so that others will know how to respond to the children.
- Sometimes, different generations have different ideas of how or when to include children when something like this happens. Some believe you shouldn't tell or involve children because you don't want to upset them. Some believe children should be protected from the pain. Experts now believe we should not protect children from what is happening in their own family and that children will have a smoother adjustment to change if they feel included and if they know, to their level of understanding, what is going on. Children then have the opportunity to work at, and to work through, their feelings at the same time as everyone else. It is important for parents to take the lead and instruct others on how to respond and what to say to the children.
- A check to gauge that you are open and honest with children is if you can talk freely with other adults on the phone or face to face, and not have to be too careful about what you are saying because the kids are around. Although they may not understand all of what you are saying, they have heard the words (e.g. chemotherapy and radiotherapy) in previous explanations to them. What they are hearing is not new, just being described a bit differently.

What should you talk about?

The disease

Tell children as soon as you can that their parent is sick.

Use the word “cancer.” Soon, and sooner than you would believe, your children will hear the word cancer connected with the illness. Let them hear it from you first.

Name the specific cancer (use the words they will hear) and then explain, in words they will understand, what it means.

“I am very sick.”

“I may look (seem) okay, but I am very sick.”

“I have a sickness (disease) called cancer.”

“There are many different types of cancer.”

“I have a type of cancer called leukemia. Leukemia means that there is cancer in my blood.” (“I have cancer in one of my breasts.”) (“I have cancer that started in my _____ and has spread to _____. ”)

The plans over the next while (what is going to happen)

Explain the treatment(s) planned for the near future — or as much as you know. Will the parent be in hospital/at home? Will their appearance change? What will be the likely side effects of the disease or treatment?

Explain how things will change for the children, and who will be looking after them. Will they be staying in their own home?

Will they still be going to their usual activities? If plans are still uncertain/unknown, tell them you will let them know as soon as you know. Try to give your children even a rough idea of the length of time the treatment and recovery may take: months; by the season (“maybe after the end of the summer”); by a certain holiday or celebration; or, “We just don’t know how long Mommy is going to be sick.” “I am going to be sick for a long time before I can get better.”

Information from other sources

It is amazing what children can hear in the neighbourhood, at school, or at a friend’s house. Explain how information can get mixed up and what they should do if they hear something that conflicts with what you’ve told them.

“If you hear something different from someone else, come ask me about it.”

“Daddy and I know best what is happening. If you hear something from someone else, come and talk to us.”

Ongoing communication

Tell the children that you will keep them up to date and that if anything changes, you will let them know. Encourage them to ask questions and talk about what they are feeling.

“Do you have any questions?”

“Do you feel you understand what is happening?”

“We want to make sure that you understand what is going on, so could you tell me in your own words what you think is happening?”

“What are the kinds of things you are worried about?”

“Do you feel like talking about anything?”

Addressing the future

- Tell your children that you will keep them up to date about the illness, treatment and planned hospital stays. Talk to them about any change of plans that may happen to their usual activities over the next few weeks or months and who will be taking care of them.
- For many parents, the hardest thing about explaining serious illness to their children is talking about the dying issue. Because of Terry Fox Day at school and/or because of the experiences of family, friends, and famous people, many school age children link cancer with dying. For most children, the question “Are you going to die?” quickly forms in their minds. As uncomfortable as it may be, this issue needs to be addressed in one of your early conversations. If you don’t address it, children will think it is off limits to discuss, and it becomes a barrier to completely open communication. Important pieces of what children need to know to help them understand the whole picture are left out, and they are left with unanswered questions.
- You can bring it up in an indirect way: “Right now the doctors feel I am going to do fine and that I will get better, but if anything changes I will let you know.” You can explain it in a direct way: “We don’t know right now how I am going to do. If it looks like I am getting sicker, and that I might die, I will tell you.” Or you can have an answer ready for when your child asks. Make sure you keep your promise if you tell them you will keep them informed.
- Your children may think about but never come right out and ask you, “Are you going to die?” They may want to

protect you, or they may want to protect themselves. As painful as it may be, it is a piece of information they need.

- If you believe that your child will not link cancer with anything serious, remember that they will hear things from others who don’t necessarily have the whole or the correct story.

Examples of ways to address the future
(depending on your situation)

“Right now the doctors expect that I will be fine. With the type of cancer I have, the medicine usually kills all of the cancer.”

“Right now everyone expects that I will do fine, and that the medicine will kill all the cancer. If things change and it looks like the cancer isn’t going away, we will tell you.”

“Some people do die from certain kinds of cancer, but with the type of cancer I have, we are all expecting that I will do just fine.”

“Nobody is sure right now if they can make the cancer go away. We all need to hope (pray) very much that what they are trying to do will work.”

“We will tell you if it looks like Mommy isn’t going to get better”

“The doctors don’t think that I am going to get better. I am going to get some treatment that will hopefully slow the cancer down so that I can live for a few months longer.”

“When it looks like Mommy is not going to live much longer, we will tell you.”

How should you respond?

- When you tell your children, get a reading from them as to how much to tell them at a time. A child may only be able to hear so much, and then need to move on to something that is normal and familiar to them. If they return to play immediately after you have talked to them, they are returning to an activity they know, and to feelings that provide security in their world. Quickly changing the subject is normal.
- Children are normally self-centered — a crisis doesn't usually change this.
- The disruption that the illness causes in the child's life can be just as upsetting and be just as much of a blow as the illness itself. Children think the world revolves around them most of the time. This thinking does not usually change when there are difficulties in the family. Don't expect complete understanding. Try to be patient and not make children feel guilty for wanting to go on with their normal routine.
- Experts believe that children cope best when there are no surprises with what is happening. Keep children up to date.
- Don't try to predict how your child is going to deal with this. With a child, as with an adult, distress comes out in many different forms: anger, crying, pretending everything is alright, acting out, temper tantrums, regression (wetting the bed, no longer toilet trained, needing a bottle), intense physical activity, needing to be physically close to the sick parent, etc. Children don't have the advantage of always

being able to talk about what and how they are feeling. They show their feelings in ways that they know.

- Distress may come out in childish ways — because they are children. Be patient and don't expect them to act more maturely than they behaved before the parent's illness.
- Don't expect a child to cope in a certain way. Don't force them to face an issue when they have given you a strong message that they are not ready to address it.
- Give children the opportunity to explore feelings, fears, and ideas so that you have a better understanding of how they are viewing things. "Have you been thinking about something that is going on that you want to talk to me about?" "Sometimes I feel scared (sad) about all this and wish that everything was the same as before. Do you ever feel this way?"
- Showing your feelings is usually more powerful than words. You can tell your children it's alright to cry or be sad, but it probably isn't as effective as showing them. Express your feelings but don't completely unload in front of your kids. They always need to feel that you are in control and that you can look after them. If you need to let loose with your emotions, get someone else to look after the kids while you have some time to let your guard down.
- Although a child may need a bit of slack now and then, for the most part, try to maintain their usual routine, rules and boundaries. Children are not ready to deal with choices at this time. More than ever they now need the security, stability and structure of knowing that some things haven't changed. Try to be consistent with normal rules.

Key points to consider

- As soon as you can, be open and honest with your children.
- Cover the dying issue right from the start. Probably the hardest thing for everyone will then be in the open and no one will have to be on their guard.
- Involve your children in what is happening so they feel included.
- Keep children informed about plans over the next while for them, their sick parent and their healthy parent.
- Avoid surprises whenever possible. Tell your children you will keep them up to date with what is going on with their parent. "If anything changes, we will let you know." If you tell them this, be sure and keep your promise.
- Tell them that if they hear things that are different from what you have told them, to come and ask you. You know best what is happening.

1. Things to consider as you talk to your children

Explaining serious illness to a child is one of the hardest things a parent could ever do. No one ever really feels completely prepared, comfortable or good at it. Most feel awkward and inadequate.

Talk to your children about what is happening as soon as possible. Children of all ages seem to have a built-in "something is wrong" detector. Although they may not realize what is wrong, they very quickly pick up that something is not right. If children are not soon told by a parent, another family member or a close family friend, they will hear about a parent's illness from someone else, often with wrong or incomplete information. Or they may interpret family disruption in their own way, blaming themselves and letting their imagination work overtime.

Not telling the truth, or not giving them all the information (at their level of understanding), can make things worse. If you are usually open and honest with your children, they need to hear what is going on from you first or you risk breaking the trust you have established with them over the years. Tell your chil-

dren as soon as you are able — they are part of the family and part of this experience.

Children tend to cope best when they are well-informed and there are no surprises with what is happening. Keep children up to date. Being open and honest with them (on their level) ensures that they will continue to come to you if they have questions or hear something different from somebody else.

Children's friends, parents of friends, neighbours, teachers — everyone has their own version of what is taking place and what is going to happen. It is important to reinforce with your child that if they hear things from others that differ from what they have been told, they should discuss it with you. When a child learns that you are open and honest, he/she will soon realize that others outside the immediate family do not necessarily have reliable up-to-date information.

If possible, both parents should talk to the child. If the sick parent is able, decide together what to explain and how. If the sick parent is unable and the healthy parent just can't bring him/herself to do it, be selective in who does talk to the children. One or both parents should be present so that everyone knows what has been said.

When discussing things with your children, talk to all of them at the same time, even if there is an age gap. The younger ones may not understand at the level of the older ones, but they will feel a part of what is going on. You don't want "secrets" in the family. The children may be more likely to look to each other for support if they all know that nothing is being kept from anyone.

The way in which a parent explains the illness, its significance, treatment and changes in family life, will depend on the child's

maturity level, past experience with sickness, and developmental stage. If you have children at different levels of understanding, you may have to explain the same thing in different ways so that each one has an explanation at their own level. The younger ones will pick up bits and pieces of the explanations you give to the older children. They will hear words that you will use in adult conversations and know that things have been discussed with them, even if they don't really understand what they are.

Explanations to your child should be in simple terms, at their level of understanding, but don't oversimplify by making light of the situation. All of a child's questions should be answered. If you are unsure why they are asking a question, try to find out where they are coming from with it. This may provide you with an opportunity to clear up misconceptions. If you can't answer a question, assure the child you will find out and get back with an answer. Clarify with a child that they understand the words you are using. To determine what a child understands, ask them to explain it back to you.

How you talk about things to your children is probably just as important as what you tell them. Lead into things gently. Don't overload them with information. Give them time to let things sink in. Keep answers short and to the point, and keep explanations simple. Be physically close to give them love and security. Children may not understand all the words, and what things mean for the present or future, but an open, honest and caring approach can help them feel secure and a part of what is happening. They can handle the news, and they will deal with it in their own way.

You may want to practice or write down what is to be said. This may not be the usual way you talk with your children, but you may feel more comfortable knowing what words you want to use. Anticipate questions and prepare answers. Having said

that, try to be spontaneous in your discussion. Once you know how you want to explain certain things, try to let the conversation go its own way. If a child does ask a question and you are not prepared, answer it as best you can. Your child is looking for honesty, not a well-formed response.

Often, different generations have different ideas of how or when to include children when something like this happens. Some believe you shouldn't tell or involve children because you don't want to upset them. Some think children should be protected from the pain. Nowadays, experts say we should not protect children from what is happening in their own family. They believe that children will have a smoother adjustment to change if they feel they are included — if they know, to their level of understanding, what is going on. Children then have the opportunity to work at, and to work through, their feelings at the same time as everyone else. It is important that parents take the lead and instruct others on how to respond, and what to say to children about the situation.

Because it is important for children to hear the same explanations from all significant people in their lives (e.g. grandparents, babysitters, family, friends, and teachers), these adults should be kept informed of what and how things have been discussed. You may want to give these adults some direction on how to respond to children's questions, fears and behaviours. Make sure everyone who is explaining or reinforcing what is going on is saying the same thing. Some parents write down explanations to give to other significant adults in the child's life, so that they have a guide and can be consistent with the parents.

Don't present children with a lot of uncertainties in your explanations of what is happening. They need a sense of security.

A check to gauge that you are open and honest with your children is if you can talk freely with other adults on the phone or in person, and not have to be too careful about what you say because the children are within earshot. Although they may not understand all of what you are saying, they have heard the words before (e.g. chemotherapy and radiotherapy) in your explanation to them. What they are hearing is not new — just being described a bit differently.

Don't whisper. It implies secrets.

Sometime, somewhere (and usually sooner than you expect), children will hear from somebody that their parent is going to die "because they have cancer." Children do not necessarily realize that the information they hear from others can often be second, third and fourth hand, and therefore not reliable. If the "dying concern" has not been addressed at home and they hear about it elsewhere, it can obviously be very scary. Children may not want to explore what they have heard with you because they are scared, and because they want to protect you, just like you want to protect them. It is important that the "dying concern" be discussed, at some level, so that children feel fully informed and they recognize fiction from fact (see "Addressing the Future" in the Quick Overview on page 12).

Dealing with the disruptions the illness causes within family life is as hard for many children as dealing with the concerns of having a parent who is sick. Children are children. They think that the world revolves around them most of the time. This thinking does not usually change when there are difficulties in the family. Don't expect complete understanding. Try to be patient and not make children feel guilty for wanting to go on with their normal routine.

Dealing with feelings is hard work for children, just as it is for adults. Most experts believe that the more children express and explore a full range of feelings, the better able they are to cope with the present and the future. Children who receive a lot of emotional support seem to be able to adjust more easily.

Probably the most effective way to get children to talk about their feelings is for a parent to express their own (e.g. talk about fears, show sadness, cry, be angry). Although a parent may tell a child to let their feelings out, actually communicating your own feelings can demonstrate to a child that it is okay to do. If an adult never expresses feelings, the child may begin to wonder if things are as serious as people are saying, because no one seems upset. Having said all that, remember a person's coping doesn't suddenly change when a crisis occurs. If a child has been private with feelings and thoughts in the past, chances are she isn't going to suddenly open up and pour out her thoughts. Give her the opportunity to share her feelings, but don't force it.

Communicate your feelings as well as the information, (e.g. Daddy is sad because Mommy is sick. I miss her).

It takes time for children to learn what the illness means to them. As they learn, they will develop ideas and feelings, many of which may be new to them. These ideas and feelings need to be acknowledged and respected by parents and other adults. Letting children know that most of these feelings are experienced by other children in similar situations — that the feelings are normal — can be very reassuring.

Throughout an illness, information and feelings change. Children should be kept up to date without surprises. Parents should explore children's ideas on a regular basis, to ensure that facts are correct and expectations are realistic.

Children deal with serious illness in bits and pieces, at their own pace. Returning to their world of play and activities helps them regroup, feel secure, and act like nothing is wrong. When they feel ready again, they can face hearing more and maybe let themselves feel the feelings that go along with it. Normal routine and play should be encouraged as much as possible.

Children, at this time more than ever, need the security of knowing that their normal limits haven't changed when so many other things have. Try to keep a balance between normal routine and bending the rules when life is disrupted.

In your discussions with your children, never make promises you can't keep.

Ask children regularly, though not too often, if they have anything they would like to talk about, or if anything is bothering them.

Ongoing checks to ask yourself

- Does your child have a correct understanding of what is happening? Is your child up to date with information? Does your child feel included?
- Does your child have a general understanding of what is going to be happening over the next while with the sick parent?
- Have you addressed the future with your child?
- Do your children know how their day will change while their parent is sick?
- Have you left the channels of communication open?
- Do you regularly ask your children how they are doing, if they have any concerns they would like to talk about?

Examples of ongoing checks to ask your child

- I've told you a lot of things today. Do you have any worries or questions about what I've said?
- I want to make sure I've explained things to you in the right way. Can you explain it back to me?
- Sometimes you hear things about (cancer, leukemia). They may or may not have to do with your mother. Instead of keeping them inside, it is important that you ask me about them.
- What's on your mind?

2. Examples of what to say

The explanations have not been grouped according to age level as each child is different and each parent talks to their children differently. You might use bits and pieces of different explanations to arrive at your own way of explaining something.

Explaining ... Serious illness

I want to explain what's wrong with your mother and what's going to happen, so you will know what is going on.

You know your mother has not been feeling too well for a while now. Well, we found out today what is wrong.

Mommy is sick. It's not like a cold or measles or like feeling bad for a few days — she is very sick. She will be sick for a long time.

Mommy will have to stay in the hospital for a long time to get better. She doesn't want to be there but she is so sick she can't be home.

Mommy is very sick. It doesn't hurt, but the kind of sick she has means that she probably won't feel like herself for a long time.

The doctors aren't exactly sure what is going on with Mommy. She is sick, probably very sick, but the doctors aren't sure what is wrong.

There is something in Mommy's body that isn't supposed to be there. It can make Mommy very sick. It's not like when you fall or hurt your knee, or when you get a cold. It's something that makes your body get hurt on the inside.

Your mother is very sick but the doctors are almost sure they can make her better.

What I have told you is what I know and understand about what is wrong with your mother right now.

I will tell you if things change.

Right now Mommy is so sick she doesn't really care what's happening to her. When she feels better, she'll stop feeling that way.

I have to take the medicine for a long time. When the summer comes, I hope that things will be back to normal.

The cancer is different in everybody's body and we don't know what will happen. Sometimes the medication works very well to get rid of the cancer, sometimes it doesn't. Everyone is doing the best they can to make me better.

It may be a long time before I can do things with you that I usually do. Although my hair will grow back and I will look the same, I will probably still feel tired for a long time.

The doctors say I have an excellent chance of getting better.

If you have any questions at all, please ask me. I don't want you to worry about this all by yourself. We need to talk about things and be open with each other.

Explaining ... Disease and treatment

Disease — Cancer

I'm sick. I have a sickness called cancer. I am going to have to stay in the hospital so the doctors can give me some medicine (treatment/care) to help me get well. It takes a long time to get well when you have this kind of sickness.

There is something inside my body called cancer. The doctors are giving me medicine (treatment) so that it will go away.

There are many types of cancers. They are all different. Some cancers are cured quickly and easily by treatment, others are not. Sometimes you die because you have cancer, sometimes you don't.

Uncle Joe had a very different kind of cancer than I have. With the kind of cancer he had, people don't usually get better. I have a different kind of cancer than Uncle Joe had.

There are many types of cancers, more than 100. Some cancers grow very slowly, others grow fast. Some cancers can be cured, some can be greatly slowed down and with some, people do die after awhile because treatment does not work. There may be a period of time that the doctors don't know if treatment is going to work, and everyone has to wait and see.

Leukemia is a type of cancer.

Cancer is the name of a whole group of different diseases. Some are more serious than others. Some cancers make people die, some don't. Many cancers can be treated so that the person gets well again. In your mother's case . . .

Sometimes you hear scary things about cancer. There are different types of cancer. I'll tell you what I know about the kind of cancer your mother has.

Cancer treatment

Chemotherapy

Mommy is getting some medicine to help her get well. The medicine is called chemotherapy. It kills the cancer little by little.

Surgery

I have cancer in one of my breasts. I have to go to the hospital to have an operation. That means that the doctor will take my breast off.

Radiotherapy

You know the special camera that takes pictures of the inside of you (your bones) at the hospital. It's called an x-ray. There's also a special kind of machine like an x-ray machine that helps the cancer go away. It's like medicine, and it's called radiation. The radiation goes into the body and kills the cancer cells. Mommy will have some purple marks on her skin to show where to point the machine so that the radiation kills the cancer.

Treatment — General

The nurses and doctors are looking after Mommy and giving her things to get her better. She can't come home right now although she wishes she could.

The doctors think the medicine will work. We hope it will.

The doctors are giving me medicine to help me get well.

Mommy can't take the medicine by drinking or eating it, so she has a tube (like a long straw) that goes into her body and the medicine goes in that way.

Doctors know a lot about taking care of people when this happens.

Treatment is what makes you get better. It is also called therapy.

Chemotherapy is when the cancer is treated with very strong medicines (drugs) that kill the cancer.

The treatment sometimes makes people look and feel even sicker than they did before starting the treatment, but that's what has to happen so I can get better in the long run. I will feel better again after all the treatment has stopped.

Side effects are uncomfortable reactions — like feeling sick, your hair falling out or feeling really tired.

Your mom's mouth is very sore. It hurts when she talks so she won't be able to talk very much.

Explaining ... Why a parent is sick

Nobody really knows why I got sick. It just happened. I didn't want to get sick and nobody made me get sick.

It's not something you can get (catch) from me. I can't give my sickness to anyone.

Although you are in the same family you are your own person. You are different from me. You are very healthy and will probably live for a long time.

You had nothing to do with your mommy getting sick. Nothing you said, did or thought made your mommy sick.

We don't know why your mother got sick. Nobody can answer that. It's one of those questions that can't be answered.

One of the hardest things we have to learn and accept is that some questions do not have answers.

Mommy is not sick because you were bad.

I don't have all the answers. I don't understand some things.

Mommy isn't sick because God is mad at her. God wants everyone to be well and happy.

God didn't want Mommy to get sick. We don't know why this happened.

Explaining ... What may happen in the future

Your mom is very sick. Right now the doctors feel she is doing well and there is no reason to think she won't get better. If there comes a time when it looks like your mom isn't doing well, I will tell you. Right now, though, no one is thinking that.

Some people do die of cancer but a lot of people get better and live to be old.

We think the treatment will work. We hope it will work.

The doctor thinks I will be fine. Lots of people who get the kind of cancer I have live for a long time, as long as anyone else. We will tell you if anything changes.

Right now, the doctors say that Mommy is doing fine, the medicine is working and is making her better. If things change, and the medicine stops working, or it looks like she may die, I will tell you.

Many people who have cancer live for a long time, as long as anyone else.

I may not live as long as other people. Nobody can say right now.

I am probably only going to live for a few more months. Nobody knows exactly when I will stop living. When it looks like I am not going to live much longer, we will tell you.

If anything changes, we will tell you.

Right now everyone expects that I will do fine, and that the medicine will kill all the cancer. If things change and it looks like the cancer isn't going away, we will tell you.

Nobody is sure right now if they can make the cancer go away. We all need to hope (pray) very much that what they are trying to do will work.

We'll tell you if it looks like Mommy isn't going to get better.

Most people get better when they have the sickness that your mother has. Sometimes, though, someone does get more and more sick until they can no longer live, and they die. We hope very much that your mother is going to do just fine, and get all better.

Sometimes things happen to people that keep them from getting better.

I will tell you if things change.

Your mother may not live as long as most people do.

It's okay to worry that your mother may not get better — everybody does. Try not to worry about it all the time though. Your mother also wants you to carry on with your life.

Your mother is not getting better — she's getting sicker.

If Mommy gets really sick and we are worried about her dying, we will tell you.

Your mom is very sick. The medication (treatment) she is getting is working to try and make her better (kill all the cancer cells). The doctors feel that she will do very well and that she will get better. Every once in awhile the treatment doesn't do everything that it should, or other things happen and people don't get better — they die. We expect your mom will do just fine. I just wanted you to know that there is a small chance that the treatment won't work. We will let you know if anything changes.

Explaining ... Change in appearance and activity

It may be a long time before your mother is like she used to be. She is going to be tired for a long time.

The medicine is very strong. It helps me to get better but while it does that it makes me _____ .

I know I look different on the outside but on the inside I'm the same and I love you very much. Maybe you could put a picture of me by your bed so you remember how I usually look.

Sometimes the chemotherapy will make your mom tired, lose her appetite and make her lose weight.

Mommy's hair may fall out but it will grow back in after she finishes treatment.

I want to do the things that we used to do, but I just don't have the energy right now. Let's think of some things we could do with you sitting on the bed with me.

Explaining ... Having some normal times

Sometimes we have to pretend that everything is okay and not think about the cancer. It's okay to do that because we know what's really happening.

You can play and be with your friends and do what you usually do. Your mother doesn't want you to be sad and sit around all day.

There will be times that you will forget what is happening with your mother and you'll just act normally. That's fine. We can't think about this all the time.

Explaining ... Telling their friends

Some friends and kids at school may act differently towards you. This is usually because they feel uncomfortable and they don't know what to do or say.

It may be good to tell _____ (close friend) what is happening to Mom so he knows what's going on. Then he'll understand why things are a bit different and why you may be acting a bit differently.

Your mom being sick is not a secret, but you may not want to tell everyone. If you tell your close friends, then they will know why things may be a little different around here.

Sometimes kids make fun of things they don't understand or they say things because they feel uneasy. Although it takes a lot

of nerve, if you explain things to them one at a time, in a quiet way, it would help them understand and they would probably stop being weird around you.

Sometimes friends are afraid they will upset you if they ask questions or talk to you about your mom. It's important to let them know what you are comfortable (or not comfortable) talking about.

Explaining ... Visiting the sick parent

Sometimes she will feel so sick and tired that she won't be able to talk. When this happens, you can make a card or picture and send it to her because you won't be able to go visit her. Sometimes she'll feel okay. When she feels okay, you can go and visit.

When Mommy is feeling very tired and sick, I will be looking after her. She won't feel good enough to have you come and see her but as soon as she feels okay she will want you to come and see her.

Your mom will not be as strong to fight off colds and a lot of the things that kids get. When there is a big chance that she could get sick from other people, you won't be allowed to go into her room to see her. Your mom needs to save all her energy right now to get well. As soon as things are better, she wants you to visit.

Explaining ... Feelings

Even if you don't think it does, sometimes your mom being sick can affect all kinds of things. Some kids find it hard at school, some kids can't concentrate on anything. Some kids can't sleep,

some kids can't help but behave badly. Usually this is because they are worried and because everything is mixed up — their feelings and their life. If you are feeling any of this, let's talk to see if we can work at making things better.

Different people feel different things about what is happening. Try to let your feelings out in some way, so they don't get all bottled up inside you.

You may feel things that you've never felt before.

Many children and adults feel very mixed up about all this. Sometimes it helps if you talk about it.

Maybe you would like to talk about it so we can try to understand what you're feeling.

This must feel like more hurt than you can stand.

When you tell me what is wrong, I can try and understand your feelings.

Sometimes you have to try things to find out what makes you feel better. I'll try and help you.

Sharing your problems and worries with people who care about you can sometimes help.

Worrying about things can take up a lot of energy. Talking about them usually helps.

Everybody shows their worries differently.

We can't make our feelings go away just because we want them to.

Everyone will find their own way of dealing with what is happening.

For many people, they feel better if they talk about what they are feeling. You may want to talk to me, but sometimes you may want to talk to someone else.

We are all going to have trouble dealing with this. We will probably feel many of the same things, so I may want to let some feelings out — or you may want to talk to me.

I am going to have bad days when I won't cope with things very well and you may have bad days too.

This will take time to get used to.

We are all going to have to prepare ourselves for some difficult times ahead.

I want you to ask me any questions you have. I may get upset when I answer them — not upset with you, but because I'm sad. It's important that we talk about them even if it hurts sometimes.

Sometimes you may not want to ask a question because you are afraid to hear the answer — don't think about it too much before asking.

The nurse told me that sometimes people in a family are afraid to show each other how scared or worried they are, so nobody ever lets each other know what they are feeling. If this happens, everybody keeps everything bottled up inside and you can feel very lonely and scared. I hope that we can show and talk about our feelings.

You may not feel that I'm spending enough time with you, or paying enough attention. If this happens, tell me — we can talk about it.

A lot of people think they should always be bright and cheery around your mom, and protect her from the sadness and things they are feeling. I think probably she would like to talk about some of these feelings, but doesn't want to upset you either. It's okay to tell her that you are sad or worried. You may find you are both feeling the same kind of things.

Sometimes you can't say or put into words what you are feeling. Don't worry, your mom knows how much you love her.

We all have our own way of showing Mom that we love her.

You don't need to act any differently around your mom. In fact, it would be strange if you changed how you are with her.

Your mom wants to hear about you and what's happening in your life. She doesn't want to always talk about being sick. Talk to her about normal things (your friends, school, activities).

I may seem very sad and upset, but I'm still able to take good care of you. I just need to let some sadness out sometimes. I'm still in control of our lives and can take care of you.

When something upsetting happens in a family, different people in your family can feel and act differently. Sometimes you can feel a certain way some of the time, and then you feel a different way another time. Then there are times when you forget that anything is wrong. Sometimes feelings get all mixed up and you can't tell how you are feeling.

Some people may feel mad, some sad, and some may not know quite what they are feeling. Some don't want to talk about things, others may want to talk about it a lot. The important thing is that everybody in the family needs to remember there is no right or wrong way to feel. We all have to be patient and understanding about how others are feeling and acting.

Explaining ... Feeling sad

I'm so sad Mommy is sick that you will probably see me crying now and then. When you are thinking about Mommy and feeling sad, you can cry too. Maybe sometimes we will cry together. Maybe it will make us feel better.

One of the ways people show how upset they are is by crying.

One of the ways people show how worried they are or how much they miss someone is by crying and being sad some of the time.

Mommy being sick makes me sad and scared. It's okay if you feel that way.

Crying helps let out sad feelings. Maybe you will feel better.

Sometimes crying helps us feel better.

I feel so sad that I have to cry. It's hard to see Mommy so sick, but holding and loving you helps . . . it makes me feel better.

Letting your feelings out can make you sad and make you start crying, but it is important to let these feelings out so they don't build up inside you.

Explaining ... Being worried

Many kids, when they find out a parent is very sick and going to be in the hospital for a long time, wonder about a lot of things. What have you been wondering about?

It's normal for you to think about these kinds of things. Let's talk about _____ .

I will be spending time looking after Mom in the hospital, but I will also be at home sometimes to be with you. When I'm not going to be home, _____ will come and stay with you.

You can't catch cancer. You can't get it from someone else.

You may worry that you have, or will get, cancer. Many kids do when a parent gets cancer. This is usually because of everything that is going on and because you are worried. If you are concerned, please talk to me.

Explaining ... Feeling angry

Sometimes kids feel mad when a parent gets sick. It changes a lot of things for a long time. It is normal to be mad at times.

Sometimes it helps to get some of that anger out. Some kids find it helpful to _____.

Sometimes we may get mad at each other, but we all know that even though we do, we still always love each other.

It is normal to feel angry that this has happened. You can show your anger by _____. You may not show your anger by _____.

I feel angry sometimes — angry at a whole bunch of things. I'm angry that everything has changed and things seem all mixed up. I'm angry because I can't do fun things anymore, and I'm angry because I can't spend time with you like I want to. You may feel like this too

Explaining ... Feeling guilty

Sometimes kids think back to when they were bad or thought bad things about their mother and wish it had never happened. Your mother loves you very much, and she forgave you for those things a long time ago. She knows that you love her.

Don't feel bad if you aren't sad or thinking about your mother all the time. She wouldn't want that. She still wants you to carry on with your normal life — and play and be with your friends.

We can always think of things we could have done differently, but we can't go back and change things. We do the best we can at the time.

It's okay to laugh and play and take your mind off your worries for awhile.

I feel guilty sometimes because I feel mad that your mom's cancer has changed everything. Then I remind myself that I'm not mad at your mom, I'm mad at the cancer.