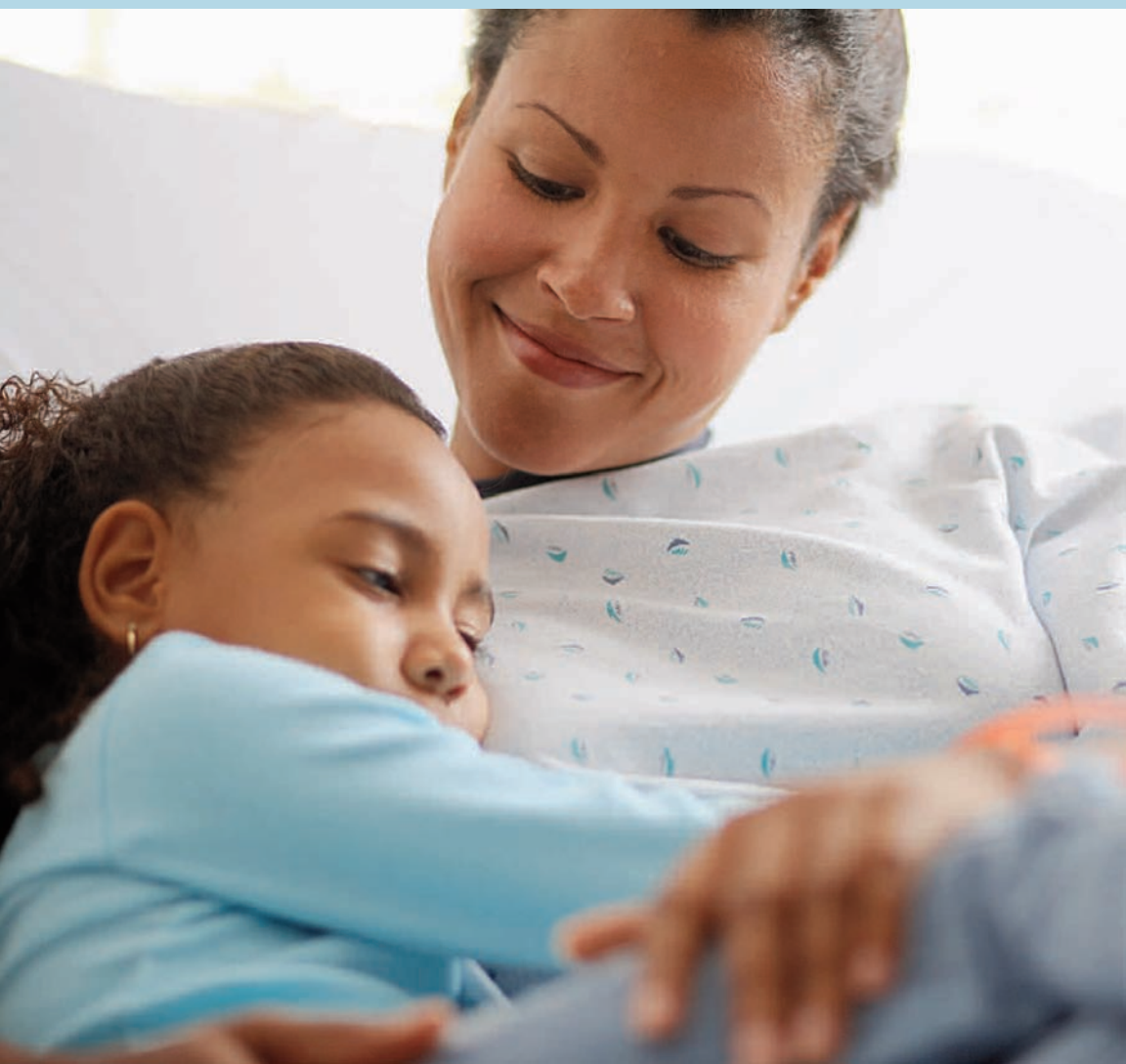


# Speaking with Children

ABOUT CANCER



THIS BROCHURE WAS MADE POSSIBLE THROUGH A GENEROUS GIFT FROM  
CAROL HAGAN, JOSEPH FARBER AND THEIR FAMILY AND FRIENDS.



## Speaking to Children } ABOUT CANCER

One of the main concerns a parent has when they are diagnosed with cancer is how the disease and its treatment will affect their children. For most parents, living with a cancer diagnosis is a new experience and requires new skills or tools for managing. The purpose of this booklet is to suggest several tools and strategies to help you communicate with your children about your cancer diagnosis.

Most parents feel a little lost about how to best speak to their children about the cancer and worry about how their children will respond to such difficult news. Fortunately, there has been much research on how to help children cope with a parent's cancer diagnosis and how to best communicate about this delicate and frightening topic.

The first part of this booklet will discuss some general information about talking to children about cancer and how families react to a cancer diagnosis. The second part will discuss more specific information about what children's needs are at various ages and developmental levels (eg. Infants and Toddlers, Preschoolers, Grade-Schoolers, Adolescents).

To begin, it is important to know that all families have different ways in which they communicate. Some families will immediately tell their children about their diagnosis at the earliest opportunity while others will wait longer, concerned that the information will unnecessarily burden their children. It is important to know that there are many good ways to go about doing this. Try not to think about there being a right or wrong way of doing this. The important thing is that you are telling them. The actual words that you use are not nearly as important as the fact that you are letting your children know. When you do this, you open the door for your children to come to you to have their questions answered and, often, their anxiety relieved.

### SOME GENERAL INFORMATION ABOUT SPEAKING TO CHILDREN:

- 1) The more children understand what is going on and how it will affect them, the less anxious they will be.
- 2) Children have great instincts and can typically sense when something is wrong. It is much better for them to hear it from you than from someone else.
- 3) Honesty is important. Children need to be able to trust that you are telling them the truth and that you will keep them informed.
- 4) Children tend to cope best when they are well informed and there are no surprises with what is happening. If they know what to expect, it will help them to cope better.
- 5) Current research has shown that it is best to tell all of your children at the same time, even if there are big age differences. Afterwards you can give more specific information based on age and developmental level. Telling them all at once conveys that there are no secrets and will allow them to better support each other.
- 6) Let other people know how you have explained your illness to your children and give them some direction on how to respond to your children's questions, fears and behaviors.
- 7) If you don't know the answers to your children's questions tell them that you will find out and get back to them.

## Preparing Yourself

Talking to your children about your cancer may be one of the most difficult things you have ever done. Take some time and think about what you want to say. It is fine to write things down and to organize your thoughts. Speak to your spouse or partner or someone on your health care team or faith community.

You may become emotional when telling your children the news. This is ok When parents express emotions it models for children that it is alright to feel sad or angry or frustrated. If you are very upset, you may want to wait until you feel more settled or have someone else help you do this.

Invite children to ask questions. Acknowledge that this is "all new to me too." Reassure them that you will go through this together and that you and others are there to provide support for them.

Pick a time to speak when there isn't a rush or other commitments. You want to allow enough time for the information you are giving to sink in and be able to answer their questions without feeling rushed. Be alert to your children's cues. Sometimes they need time to absorb the information and will have no questions at that time. Once you open the door to communication by telling them, you will have many other opportunities to 'check in' with them over time.

## Some questions you can ask

TO CHECK YOUR  
CHILD'S UNDERSTANDING

*"I've told you a lot of things today, do you have any questions or worries about what I 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 from other people. They may or may not have to do with what I have. Instead of keeping it inside please ask me if you have questions or concerns."*





**FOUR WAYS TO HELP CHILDREN OF ALL AGES COPE WITH CHANGES  
BROUGHT ABOUT BY YOUR CANCER DIAGNOSIS ARE:**

**1) As much as possible stick to your child's normal routine:**

- Mealtimes, bedtime, school, after school
- Express interest in the child's daily activities
- Use consistent familiar caretakers
- Use school as a haven where there is an opportunity for normalcy

**2) Protect family time:**

- Limit discussions about cancer with friends and extended family during family time
- Limit visiting well-wishers
- Limit phone calls during meals
- Choose a close family member or friend to be the 'go to' person for information

**3) Communicating about cancer:**

- Use honest and accurate language that your child can understand –  
Invite the child to tell you what he/she has noticed
- Don't flood children with details
- Ask "are you hearing too much or too little?"
- Welcome all questions warmly
- Listen for the question behind the question.  
What is your child really worried about?
- Questions do not need to be answered immediately
- Tell your children to "never worry alone"
- Encourage children to share what they hear from others

**4) Essential Messages:**

"Mom or dad has a disease called cancer."

Discuss the cause of cancer. Assure your child that the cancer is not caused  
by their behavior or the parent's stress.

Tell your children where the cancer is in your body and how you will be treated.

Let your children know you may feel tired or sad sometimes.

## Tailoring your message

TO YOUR CHILD'S AGE  
AND DEVELOPMENT

Of course, children of different ages have different levels of knowledge and different abilities to understand your cancer diagnosis. Again, this is very general and there will be some variability in each child and family. You know your own child best and will know where they fit in this description.



# Infants and Toddlers

AGES 0 – 2

## RESPONSES TO PARENTAL ILLNESS

Children who are very young may be aware of their parent's absences but generally will not understand the reason. Children at this age are sensitive to changes in their routine as well as changes in the emotional climate in the home. They may also have greater difficulty with separation, may be fussier and less flexible and may have changes in their sleep patterns.

## How to help them

Maintain consistent routines and caregivers as much as possible. Give written instructions to people who may not be familiar with caring for your children so there can be consistency (meals, bedtime, bathing). Children this age do best having frequent, brief visits with ill parent if the parent is able. Creating a 'portable environment' for children this age can help such as having familiar items such as their crib, blanket, toys etc. Describe the illness to toddlers in the simplest possible terms (e.g. "Mommy has a boo-boo. Mommy's medicine makes her hair go away but Mommy will be ok")



## *Maintain consistent routines*

AS MUCH AS POSSIBLE.

# Preschoolers

AGES 3 – 6

## RESPONSES TO PARENTAL ILLNESS

Children this age have a beginning level of understanding about illness. There may be regression to earlier behaviors such as separation anxiety, bedwetting, thumb sucking, fear of the dark, baby talk. They are often very sensitive to changes in their routine. Their questions tend to revolve around themselves and their needs. Children at this age may believe that they caused their parents' illness (this is called magical thinking). Children may think that they can "catch" the same thing as their parent.



## How to help them

Children this age do not need a lot of detailed information. They will tend to focus on the cancer symptoms or side effects that they can see, such as hair loss. It is helpful to use a doll or picture books to help talk about illness and where it is (eg. point to stomach). Reassure them that they did not cause the illness and that they can't 'catch' it either. Correct other misperceptions they might have. Reassure them that they will be taken care of and maintain as much routine and consistency as possible. Continue usual discipline and limit setting and provide outlets for aggression that are positive; such as play and physical activity. Be patient with regression as it should get better with time. School should be a place where their lives can be normal. Ask teachers to keep greetings upbeat, do not update teachers about your cancer in your child's presence (call later or write a note).

Keep conversations about illness brief and repeat when necessary. Try to explain the treatments and procedures that you will have in terms of how it will affect them and their routine. For example "I will be having chemotherapy next week so I won't be able to take you to soccer practice. I have asked Julie's mother to take you to practice and bring you home afterwards." Another example "The medicine that the doctor uses to fight my cancer cells will also make my hair fall out. Sometimes I will wear a wig and sometimes I will wear a baseball cap to keep me warm and comfortable but my hair will grow back."

*Keep conversations about illness brief*

AND REPEAT WHEN NECESSARY.



## Grade-schoolers

AGES 6 – 13

### RESPONSES TO PARENTAL ILLNESS

School-aged children will understand more about the causes and effects of serious illness, but you should still keep your explanations simple. This age group may still need to be told that they did not cause your illness and that it is not “catching” or you can not catch it. They may hesitate to bring up a concern or a fear they have because they are afraid of burdening the parent who is facing cancer. They may go off and play as though unaffected by what they are being told. Often there are later reactions or they may show their response through behavior (such as acting angry or being quieter than usual) rather than words.

Older elementary school students are often more familiar with the basics of the human body so use their knowledge as a starting point for your conversation. Children this age can be given more details such as the name of the cancer and the basics of your treatment plan. They will often ask blunt questions and may have some disconnect between how they are thinking and feeling such as making jokes about hair loss. This age group may have some physical complaints and make more trips to the nurse’s office at school. They may have difficulty concentrating at school and they may have some separation anxiety around activities outside of the home.

## How to help them

It is a good idea to check in with them once a week to see how they are doing and if they have any questions. By encouraging them to talk about their concerns, you are teaching them how to handle crisis in a positive way, and you will also have a sense of how your child is coping. Be sure to watch for changes in school performance, as well as eating and sleeping patterns. Use books to explain illness, treatment and potential outcomes. Cancer cells can be described as cells that grow that don’t belong there. Treatment involves taking medicine to kill the cells or having a surgeon take them out. Explain to your children what they can expect in terms of changes in their routine and schedule. Reassure them that they will be taken care of and not forgotten. Children this age tend to get upset by prolonged expressions of sadness by their parents. So while a little bit of expressed sadness is ok, it should be kept at a minimum. Continue usual discipline and limit setting.

Communicate frequently with teachers and the school counselor, if helpful. Encourage teachers to give advance notice of projects and needed supplies, so your child feels prepared and has what she/he needs for school. A class parent or friend’s parent can also be helpful with this. Support continued, consistent engagement in school and activities. Don’t assume a link between child’s complaints and parent’s illness. Explore what is going on with the child which may be a normal school/development related issue. Ask the child’s teachers to listen but not probe and have teacher and friend’s parents share the child’s comments with you. Tell your child “Don’t worry alone.” Find and use the child’s best time to talk such as the car or at bedtime.

# Adolescents/Teenagers

AGES 13 – 18

## RESPONSES TO PARENTAL ILLNESS

Children at this age can understand most aspects of cancer. Each child responds differently to their parent's illness. Some may get angry and distant; others may feel insecure and scared. Many kids this age are worried about being different and may turn feelings inward. They may become withdrawn, angry or anxious. There is often increased reliance on friends and other non-parental adults. They may worry about the future in terms of what will happen with their family, money, and other "what ifs."



Children this age often want to be more independent and treated like adults. Many will criticize how parents are handling things. They are more likely to deny fear and worry in order to avoid discussion. At this age, your sons and daughters have heard a lot more about disease and cancer than their younger siblings. As a result, they may be quite worried, but afraid to upset you – or themselves – by asking questions or bringing up your diagnosis.

## How to help them

**D**on't expect adult-like behavior or impose adult responsibilities. Respect teen's coping style and wishes for privacy. Take your cue from them whenever possible, and share as much information as they seem to want and are ready to handle. While they may appear in control as you talk together, be prepared for some emotional response, either as your discussion continues, or at some later time. Individualize school expectations, allow for a little bit of flexibility. Plan activities for the whole family as you are able. Watch for signs of depression, substance abuse, increased risk taking.

With respect to discipline, try to maintain the same rules. This makes children feel safer. It may be important if a child's behavior changes to look at the emotion behind the behavior when deciding on enforcement of rules.

If your child worries a lot about you, remind them that they are not responsible for your health. You don't want them to give up their friends and activities.

*Plan activities for the whole family*

AS YOU ARE ABLE.



## Some particular issues/questions

### **Be prepared for your children to ask “Are you going to die?”**

It is usually best to give an honest answer in a language they understand, while at the same time making sure they are not too anxious. Whenever possible, share some positive information.

“People do sometimes die from cancer but I am going to do everything possible to make the cancer go away.”

“Mommy/Daddy has very good doctors and will have the best treatments available to treat the cancer.”

“Mommy/Daddy is going to do everything possible to treat the cancer so I can get better.”

“Right now, the doctors say that I am doing fine and that the medicine is working. If things change we will tell you.”

“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.”

## Hospital visits

**Try to prepare children ahead for any time you are admitted to hospital, including explaining to them who the caregiver/s will be.**

- Support any child who wants to visit a parent in the hospital
- Inquire further about children who don't want to visit
- Prepare them in advance, tell them what they might see
- Provide structure during the visit
- Have some time to talk afterwards, allow them to de-brief
- Bring an extra supportive adult if possible

## Remember

THERE ARE MANY WAYS TO SPEAK  
TO YOUR CHILDREN ABOUT CANCER.

**The important thing is that you are telling them and giving them an opportunity to ask questions and feel supported and “in the loop.” It is difficult to predict every child’s reaction and all children respond differently. It is also difficult to accept that you cannot protect your child from this illness. Try to remember that children are resilient and learn to live with this.**



This booklet is just one of many resources to help you with this difficult task. There are many types of cancer with many different treatments and outcomes. We would be glad to provide more specific information should you need that.

There are some ongoing signs that might indicate your child needs additional help. It is important to intervene if these following signs last for a long period of time.

- The child is constantly thinking about your cancer and little else.
- The child has numerous fears you will die despite reassurance to the contrary.
- They have recurring thoughts of death or wanting to die.
- The child feels different and ashamed.
- He/she cries easily and often.

Try to be patient with your children's reactions. Be patient with yourselves as well. This is a very stressful time for you and your family and sometimes you may say or do things you feel badly about. It is important to forgive yourself and others and offer an apology if needed. Helping children cope with a parent's cancer is often a process that goes on for months and years. There will be many opportunities to provide information and support during this time. If you simply listen, answer questions honestly and help your children feel included, you will go a great distance towards making this experience much less frightening for them.



**If you would like to speak to a counselor at The Abramson Cancer Center to discuss these issues or other challenges you may be facing, please call 215-615-0534.**

The following sources were consulted in the production of this brochure:

- 1 The Dana Farber Cancer Institute Family Connections  
"For Parents: Talking with kids about cancer"
- 2 "Cancer in the Family: Helping Children Cope With a Parent's Illness.",  
American Cancer Society, 2001 and [www.cancer.org](http://www.cancer.org)
- 3 Y-me.org How to Talk to Your Children

## **ABOUT THE ABRAMSON CANCER CENTER**

The Abramson Cancer Center of the University of Pennsylvania is one of a select group of cancer centers in the country awarded the prestigious designation of *Comprehensive Cancer Center* by the National Cancer Institute. This status reflects our outstanding research, clinical services, education and information services, and community outreach. The Cancer Center is comprised of over 400 doctors and scientists, all of whom are dedicated to increasing knowledge concerning the prevention and cure of cancer. Penn's Cancer Center offers multidisciplinary evaluations, so patients can receive diagnoses and treatment options quickly and easily, as well as comprehensive treatment services for all types of cancer. As part of the University of Pennsylvania Health System, we are able to build upon the resources of one of the nation's foremost medical centers, enabling us to address all of our patients' medical needs. We are committed to treating each patient as our only patient, while pursuing our understanding of, and ability to fight cancer.

## **ABRAMSON CANCER CENTER WEB SITE**

Patients and families can learn quickly about the comprehensive cancer services and experts at the Abramson Cancer Center by visiting our website. There is also information on clinical trials, special events and general information about specific cancers. Visit [pennhealth.com/Abramson](http://pennhealth.com/Abramson)

## **ONCOLINK®**

Oncolink is the Abramson Cancer Center's award-winning internet resource. It contains information about all aspects of cancer, the latest treatments, research advances, support services and related issues. Through Oncolink you can access information from the Abramson Cancer Center, the National Cancer Institute and other sources. Visit [www.oncolink.org](http://www.oncolink.org)

## **TOLL-FREE CANCER INFORMATION**

The Abramson Cancer Center makes it easy to request the latest information about cancer. With one toll-free call, you can ask questions about cancer treatment and research, request free brochures, and find out about our Cancer Center. Call 800.789.PENN (7366) and ask to speak to one of our cancer line nurses. They are available to take your call Monday through Friday, 8:30 am – 5:00 pm.

The University of Pennsylvania's Abramson Cancer Center is proud to be a





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