

Talking to Children When a Loved One Has Cancer

CANCERCARE[®]
CONNECT
BOOKLET SERIES



CANCER*care*[®]

WWW.CANCERCARE.ORG



CANCER*care*®

The CancerCare Connect Booklet Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects and coping with cancer.

To order free copies of this booklet, please use the online order form on our website, www.cancercare.org.

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers and world-leading cancer experts.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at www.cancercare.org/donate. You may also mail a check, payable to CancerCare, to CancerCare, Attn: Donations, 275 Seventh Avenue, New York, NY 10001.

Thank you.

CancerCare®
National Office
275 Seventh Avenue
New York, NY 10001

Toll-free 800-813-HOPE (4673)
Phone 212-712-8400
Email info@cancercare.org
Web www.cancercare.org

The content of this booklet is independent, non-promotional and free of commercial influence and bias.

Talking To Children When a Loved One Has Cancer

TABLE OF CONTENTS

Introduction	2
Talking About the Diagnosis	4
Talking About the Treatment	7
Talking About the Prognosis	10
Special Considerations When Talking to Teens	11
When a Child Has Cancer: Helping Siblings Cope	13
Keeping the Lines of Communication Open	15
Conclusion	16
Frequently Asked Questions	17
Resources	21

EDITOR

Lauren Chatalian, LCSW

Women and Children's Program Manager, CancerCare

Good communication with your children helps everyone in the family cope with whatever changes lie ahead.

Among the many difficult questions parents face when a family member is diagnosed with cancer is “What do I tell my children?” Fearful that they might upset or worry their youngsters and teens, some parents withhold the news. But even at a very young age, children can sense when something is wrong. If not told the truth, they might imagine that things are worse than they really are or even that they themselves are the cause of the problem.

Talking to a child about a parent's, grandparent's, sibling's or other loved one's cancer and how it will affect the family isn't easy, but it is necessary. This booklet can help. It includes tips for talking with children about a family member's cancer and treatment. It also suggests ways to help children cope with some of the feelings they may experience during this time. As their parent, you are the best judge of how to talk to your children. The first conversation about cancer is often the hardest, but by speaking honestly and helping them express their emotions, you make it easier for them to feel safe and secure.

For more than 75 years, CancerCare®, a national nonprofit organization, has helped people with cancer and their loved ones. Our free services for children affected by cancer help parents and children cope with a cancer diagnosis in the family. We have professional oncology social workers on staff who are specifically trained to understand the complex needs of children and families. They provide case management, counseling and workshops and design activities that bring families together in a relaxed setting, which is reassuring to children.

Support groups led by our social workers are a good place to exchange information and share experiences with other people in similar situations, which can make it easier to cope.

Our social workers also help you find the practical help you might need, such as financial assistance or tips on managing side effects. All of CancerCare's services, offered by telephone, online and face to face, are completely free of charge.



Talking About the Diagnosis

It may be beneficial to discuss a cancer diagnosis with your children as soon as possible. Sharing this information may allow children to feel valued and can help maintain trust in your relationship and help them through a frightening experience. This may also relieve some of the stress you've anticipated in telling them.

Prepare what you want to say. It may be helpful to practice or write down what you would like to say before your first conversation. You could also consider who you would like to be present during this conversation, such as a spouse, partner, relative or close friend. If you have children of different ages, you might speak with your older children first. The older children may even want to help you tell your younger children. Try to have these conversations as close together as possible so that all members of the family are aware of the situation and have a chance to support each other.

Set the tone. It is important to be mindful of how you would like to share this information with your children. Speaking in a calm and reassuring voice can help to set the tone of the conversation. However, this may not always be possible. Avoiding strong feelings can lead to more distress. The display of emotion and even crying can be good ways to cope. A parent expressing sadness can show children that it's okay for them to do the same. Your children will take cues from you.

If your children become upset, validate their feelings. Share that you understand how challenging these feelings can be. If it feels like too much to discuss at one time, reassure them that the door is open to continued communication on all sides.

If you don't know the answer to their questions, let them know you will find out and get back to them as soon as possible. This teaches children that although parents don't always have all the answers, they will do their best to help. This also lets children know that they have permission to ask any questions they like.

Consider your child's age. When speaking with your children, use words that are common and familiar; your children will have an easier time understanding what cancer is and what to expect. Remember that young children can have short attention spans, even when it comes to important subjects. You may need to have more than one conversation about cancer with your child. In addition, keep in mind that children at different ages have different ways of understanding things. Every parent knows their child's level of maturity and comprehension, but you can use this information as a guide to what works best with different age groups.

Consider using simple and concrete terms. For example, you might say:

“Mommy is sick with an illness called cancer. The cancer happened on its own—nobody did anything to make it happen. My doctors are doing the best they can to take care of me, and I am going to do everything possible to get better.”

It is also important to let children know that cancer is not contagious. Young children often think of being sick in terms of catching germs. Let them know they can't catch cancer like a cold. Tell them you can hug and kiss each other just like always.

You may notice that children between the ages of 5 and 8 can be focused on themselves. This does not mean that your child is selfish in any way, but rather the developmental stage they are in. A common question they may ask could be “Who will take care of me?”

At their developmental stage, they see the world from their point of view and do not see the larger picture until they get older. Letting them know that they will be taken care of and that you will have a plan in place will help them cope with any changes to their routine.

Children age 8 or older are likely to have more questions. Be prepared to answer their questions to the best of your knowledge, but keep in mind that it is okay not to have all the answers. You can share that you will check with our doctor and update your children when you have more information. This will give children the chance to absorb information at their own pace; perhaps they will have more questions later.

No matter what their age, it's important to let your children know that what they are feeling is normal and okay and that their needs will continue to be met. Finding out what they might have heard about cancer is helpful in order to clear up any misinformation. Be honest and hopeful. Having frequent conversations will help your children feel more secure and part of your healing process.

Ask professionals for guidance. If you need guidance before talking with your children or at any time afterward, contact CancerCare. Our team of professional oncology social workers can help you find age-appropriate ways to answer your children's questions and concerns and can refer you to helpful resources.

Talking About the Treatment

Whether you choose to talk about treatment plans early on or at a later date, the important thing is to keep your children informed. Since treatment may bring about many changes in your family's day-to-day life, encourage your children to ask questions if they are concerned or confused. Here are some suggestions for talking to children about the treatment plan:

Let children know about any changes to their routines. When talking about treatment, many children want to know what it will mean for them. For example, if a parent is in the hospital, who will take them to school, make dinner or take them to after-school activities? Let your children know that these concerns are important to you, too. If you don't have your support team (relatives, neighbors, friends) in place yet, reassure your children that there will be a plan and that you'll continue to keep them updated.

Prepare children for possible treatment side effects. Watching a loved one experience side effects can be upsetting to children. Chemotherapy and other medicines can cause hair loss, weight loss, rash or nausea, for example. If children understand in advance that the side effects are part of the treatment and not part of the illness, this may help children prepare for what they could expect to happen. With younger children, you might use crayons and paper to make simple drawings of some of the changes that might occur, such as hair loss. This will give your child a more concrete way to understand that there will be changes with the treatment.

For most children, you do not need to go into a lot of detail about side effects. For example, you might tell a child, "Grandma has to take very strong medicine to get rid of the cancer. It might make her lose her hair and feel sick, but it will be from the strong medicine, not the cancer."

If a treatment involving radiation is involved, you might say, “Your sister is going to have a treatment that might make her very tired. When she gets home, she will need lots of rest,” or “Grandpa may not be able to play with you as often as he wants, but he loves you very much.”

Because different people respond differently to treatment plans, let your children know if you’re not sure about what the side effects might be. But reassure them that you or another important person in their life (parent, close relative, family friend) will help them prepare for any changes. Providing this kind of comfort and support shows how important it is to you to keep your children involved in an extremely difficult time.

Help children stay connected during treatment. One way to help your children cope with cancer is to help them feel connected. For example, if you’re going to be in the hospital, your children might draw pictures for your room or send cards. If you’re able, you might want to make a drawing or send a note home to them as well. This will help children continue to feel involved even if they are not physically present.

Helping children stay connected at home is also important, but it might be difficult for the person with cancer to do some of the things they were able to do before. For example, cancer and cancer treatment may prevent a parent from lifting or carrying a toddler or young child. The child may miss this and want to be close. By hugging each other from a seated position or lying down with the child on the floor, couch or bed, they can be at eye level with the parent and feel comforted. Unstructured activities, such as watching TV or talking about their day at school, can also bring a sense of togetherness.

You may also find that your child wants to help but doesn't know what to do. Giving children simple tasks, such as bringing water or an extra blanket to the person with cancer, helps them feel connected. Teenagers can take on larger tasks around the house, such as washing dishes or mowing the lawn. This does not mean that children or teens should be expected to take on adult responsibilities, such as paying bills, but specific concrete tasks can help children feel useful.

Let your children know that you are thankful for their help, but that you don't expect them to take care of you all the time. That is not their job. Their job includes things like going to school, doing their homework, seeing friends, playing sports and having fun. Children should not feel guilty about being children. Let them know that although you (or another family member) have cancer, a cancer diagnosis does not define your family. Remind them often that no matter what changes the cancer might bring, the foundation you have created as a family will never change. You will continue to show your love in every way you can.



Talking About the Prognosis

As with any discussion about cancer, consider the age of your children when discussing the long-term prognosis of recovery. Give only as much information as needed for their age. The most important thing is to let your children know you will be honest with them and that they can come to you with their concerns.

Continue to be mindful and aware of any emotional changes in your children that might indicate they are stressed from worry. Explore if your children have been misinformed in any way. Sometimes children may hear something misleading from other sources leading them to imagine something that is not true. Depending on your children's age, they may also have access to inaccurate information on the internet. Try to check in with your children about this and monitor the sources they are receiving information from. Check to see if they might have misinformation. Sometimes children hear something misleading from other people and imagine something that isn't true.

No matter what the prognosis, some children will want to know from the beginning if their loved one is going to die. You can start by saying that, with the doctor's help, their loved one will be doing everything possible to get rid of the cancer and get better. If the cancer is advanced and aggressive, you can still tell your children that the doctors are doing their best to treat it and that you'll let them know how the treatment goes.

Often, it's a good idea to speak with a professional counselor if your children have questions about death and dying. Young children and older children understand death in different ways. If your family is dealing with a difficult prognosis, CancerCare can help. We provide case management, counseling and referrals to support services close to where you live.

Special Considerations When Talking to Teens

The teen years are often difficult in general due to various reasons. Teenagers may be experiencing identity, self-esteem and relationship challenges aside from the news of any cancer diagnosis. Talking to your teenager about a cancer diagnosis, treatment and prognosis may be very different than approaching these conversations with younger children.

Teens are in a developmental stage of life. They are finding their own identity. Peer pressure, demands of school are at the age when people try to figure out who they are as they move toward independence. Peer pressure, demands of school and worries about the future are common challenges for teens. If on top of that a parent or family member is diagnosed with cancer, teens may have an especially hard time.

This doesn't mean they won't be able to cope. But it does mean teens are likely to have different needs than younger children. Here are some tips for talking to teens:

Be prepared with specific information about their loved one's diagnosis and treatment. Answer teens' questions openly and honestly, and let them know of people and places they can go for more information.

Respect your teens' privacy. Teens may want to talk only to certain people about their loved one's illness. Make sure there are other people, such as close relatives or family friends, who they can go to, but try to come to this decision together.

Strive for consistency. Continue to encourage teens to spend time seeing their friends, keeping up with schoolwork and going to social activities. Let them know that you think it's important for them to be teenagers and that it's okay to have fun in spite of coping with cancer.

Avoid role reversal. When a parent or loved one is sick, teens may feel the need to take on the role of caregiver, whether it involves caring for and adult who is sick, or for younger siblings. However, it's important for teens to know that they will continue to be cared for. Acknowledge their concerns, but reassure them that their responsibilities of being a teenager have not changed.

Be aware of teens' special concerns. Teens might have special concerns such as whether they will get the same form of cancer. Check with your medical team about how to best answer these questions, such as regarding hereditary diagnoses. Your teen might be concerned about the cost of treatment and wonder if there will be money for college or other big expenses. Offer whatever reassurances you can to these concerns. If you are unsure of what may be financially feasible moving forward, continue to share that you are doing everything you can so they can feel financially secure. CancerCare can help your family with questions about financial assistance to help manage these concerns.

When a Child Has Cancer: Helping Siblings Cope

Sometimes it is a child, not an adult, who is diagnosed with cancer. Here are a few tips to help siblings cope:

Let siblings know that nothing they did or said caused the cancer. The cancer happened on its own. It is not anyone's fault. Make sure young children know that it's not contagious.

Prepare siblings in advance for changes. When the child with cancer starts treatment, there may be side effects such as hair loss or weight changes. Let siblings know ahead of time that these side effects might happen and that they are part of the treatment to help their sibling get better.

Include siblings in what's happening. Be available for any questions or concerns family members might have. Be honest and hopeful. If the child with cancer is in the hospital, siblings may want to draw pictures, send cards, talk on the phone or visit. At home, find ways for the child with cancer and their siblings to spend time together in relaxing, stress-free ways. For instance, they could watch a movie together or play a board game.

Try to make as much time as possible for your other children.

Having a sibling with cancer is very emotional. In addition to being worried about their sibling, your other children may feel sad that you don't have much time for them. They may even feel jealous that their brother or sister is getting so much of your attention. Feeling this way might make your well children feel angry or guilty. Be available to talk things over and let them know it's okay to have strong feelings.

Remind them often how special they are and how proud you are to be their parent. It is possible that siblings may feel as though they are not receiving as much attention as your child who has been diagnosed with cancer. While this may be true, continue to offer a space for your other children to continue to feel important and valued as well.



Keeping the Lines of Communication Open

Good communication with your children will help everyone in the family cope with whatever changes lie ahead. Here are some tips to keep communication flowing:

Let your children know they can always come to you and that you will tell them the truth. Be honest and hopeful.

If they have trouble talking about cancer, suggest to your children that they try writing down their questions and concerns. Your medical team and CancerCare can help you find answers for anything you're unsure about. Use games or arts-and-crafts projects. Children are more likely to identify and communicate their feelings through play activities. They will tell you how they feel just by drawing a picture of something that's on their minds.

Schedule family update meetings when children can discuss what's on their minds, share how they are feeling and find out new information.

Build a support network. Speak with your spouse or partner, close friends or your child's teachers and guidance counselors at school about being available should your child need additional support. Make sure your child feels comfortable with this.

Try to spend relaxed, stress-free time with your children to talk about their hobbies, school life, friends and activities. Help them feel free to talk about fun things. Let them know that cancer is only one of many things to talk about. Enjoy being together.

Don't be afraid to ask for help. CancerCare provides free case management, counseling, education and practical help for families coping with cancer. All our services are free of charge.

Conclusion

Learning that someone in the family has cancer is an emotional experience for children. They might feel afraid, confused, guilty or angry. In fact, they are likely to feel different things at different times.

If you help your children stay informed and connected, they will have an easier time coping with the changes that cancer brings. Let them know that strong feelings are normal, and encourage them to speak freely and openly. CancerCare and the resources at the back of this book can help.



Frequently Asked Questions

Q: Ever since I told my son about my cancer, he has been acting out at school and wanting to stay home. What can I do?

A: Chances are your child is very worried about your cancer and may want to stay home to make sure you're okay. Perhaps he thinks you need him to help out. Reassure your child that it's okay to feel angry and upset, but that while you work hard to get rid of the cancer, you need him to work hard at school and to keep up with his homework, his friends and his activities. Give him lots of praise for his efforts, and try to spend some relaxed, unstructured time together after homework. Children need to know that their parents are in charge. The routine of school and consistency of everyday activities help children feel safe and secure.

Be sure to speak with your child's teacher or principal to explain the changes in your household. Your school district is likely to have trained professionals who can help your child deal with the difficulties he is having. In addition, the professional oncology social workers at CancerCare can be called upon for help and advice.

Q: I am currently in remission, but my daughter wants to know if the cancer will come back. What should I tell her?

A: Remission (the disappearance of cancer and symptoms as a result of treatment) is certainly great news. Let your child know how happy you are to be in remission and that you are looking forward to enjoying time with your family. If your daughter is concerned that the cancer will come back, you should tell her there is no sign of the cancer now and that you are optimistic that things will stay that way. Let her know that you and your doctor will be doing everything possible so that you stay cancer free. If there's any chance of a recurrence (the return of cancer and symptoms after successful treatment and being cancer free), tell her you will let the family know so you can deal with it together.

Q: What if I get upset or start to cry when talking to my children about cancer?

A: Speaking with your children about cancer, even if you write down or practice what you are going to say, is bound to be difficult. At the start of your conversation, tell your children that you might get sad or upset during your talk. In this way, they will be prepared for your emotions. If you feel you are going to cry and have difficulty continuing, stop a moment and take a few slow, deep breaths. It does not hurt children to see their parent feeling sad or crying. If your children comfort you—for example, by giving you a hug—it is important to praise them. No matter what the circumstances, it's never a bad thing to know that your child has developed empathy—the ability to be sensitive to and identify with another person's situation and feelings. When you feel calm, begin again. This will show your children that even when people have strong feelings, they can manage. You will learn from each other how important it is to keep talking and supporting one another. The important thing is to stay connected.

Q: What if the treatment makes me feel too sick to take care of my children?

A: If possible, it's best to have a plan in place before your treatment begins. Since there is no way to predict how your particular treatment will affect you, it's good to make sure you have plenty of support. Your spouse or partner may be busy with work, helping you get to your doctor and taking care of you, so you may need to call on others for a while. One way is to ask someone your child knows well, such as a family member or close friend or relative, to act as a coordinator. When other friends or neighbors ask what they can do, this person can put things in motion.

For example, someone might help with meals, while another might help getting your children to school or help with grocery shopping or other chores.

If you put a schedule together of your children's activities, your coordinator can help your children keep as normal a routine as possible. If your children are invited for sleep-overs and outings, it will give you time to rest. Friends, relatives and neighbors know that when they help out, they are giving you time to concentrate on getting better. Don't be afraid to ask. If you need additional help with daily tasks, CancerCare can refer you to services in your area and can help with emotional, practical, and financial concerns.

Q: My teenagers want to meet my doctors and see the hospital. Is this a good idea?

A: It is not unusual for teenagers to express an interest in learning as much as possible about their parent's cancer, including meeting the doctors and seeing the treatment facility. This is a good idea. You might ask your doctor to set aside time to meet with your teens, so they can ask questions and your doctor can suggest resources or appropriate websites for reliable information. When you allow your teens to demonstrate their ability to handle things in a mature way, you show them that you have confidence in them. Let your teens know how proud you are of them and stay in touch with their feelings.



Resources

CancerCare® for Kids

800-813-HOPE (800-813-4673)
www.cancercares.org/forkids

American Cancer Society

800-227-2345
www.cancer.org

National Cancer Institute

800-422-6237
www.cancer.gov

Sibling Support Project

425-362-6421
www.siblingsupport.org

SuperSibs!

888-417-4704
www.supersibs.org

The Dougy Center

503-775-5683
www.dougy.org

BOOKS

Butterfly Kisses and Wishes on Wings

By Ellen McVicker
www.butterflykissesbook.com
2006

How to Help Children Through a Parent's Serious Illness

By Kathleen McCue, MA, CCLS and Ron Bonn
St. Martin's Griffin; New York, New York
2011

Cancer Hates Kisses

By Jessica Reid Sliwerski and Mika Song
Dial Books; New York, New York
2017

This booklet was made possible by AbbVie and Bristol Myers Squibb.



CANCER*care*®

Help and Hope

WWW.CANCERCARE.ORG

800-813-HOPE (4673)