### Helping Children When a Family Member Has Cancer

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.



CancerCare helps individuals and families better cope with and manage the emotional and practical challenges arising from cancer. Our services—for patients, survivors, loved ones, caregivers, and the bereaved—include counseling and support groups, educational publications and workshops, and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge. CancerCare is a national nonprofit organization founded in 1944.

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 send a check payable to CancerCare; mail it to: CancerCare, 275 Seventh Avenue, New York, NY 10001, Attn: Donations. Thank you.

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# 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, or sibling's cancer and how it will affect the family isn't easy, but it is necessary. This Cancer Care Connect® 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.

For more than 65 years, Cancer Care®, 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, people specially trained to understand the complex needs of children and families. They provide 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.

By talking with your children honestly and helping them express their emotions, you make it easier for them to feel safe and secure. And as their parent, you are the best judge of how to talk to your children. But the first conversation about cancer is often the hardest. The information in this booklet will help you start that conversation and give you the tools to keep it going every step of the way.



### **Talking About the Diagnosis**

It's usually best to talk with your children soon after the type of cancer (the diagnosis) is known. Sharing information early on will help build trust. When children know they are being kept informed, it helps make the experience less frightening. This is not to say that talking about cancer is easy. Here are some tips for talking to your children about a cancer diagnosis:

Prepare what you want to say. Many parents find it helpful to practice or write down what they want to say before the first conversation. Other parents feel that having their spouse, partner, close friend, or a relative with them makes it easier. Parents also tell us that choosing a quiet time when they and their children are rested makes the conversation less stressful.

If you have children of different ages, you might speak with your older children first. Perhaps, the older children will 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.** As important as *what* you say is *how* you say it. Try to use a calm and reassuring voice. It's okay if you become sad or feel like crying. Some adults and children who think of crying as a sign of weakness will bottle up their feelings inside, causing more distress. However, crying can be a good way to cope. When a parent expresses sadness through crying, it shows children that it's okay for them to do the same.

If your children become upset or wander off, tell them that you know this is a tough conversation and you understand how they feel. You can always come back to it later.

Remember that children, especially young ones, tend to have short attention spans. Do not talk longer than they can listen, but be sure to ask them if they have questions. If you don't know the answer, 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 their children. 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.

In addition, keep in mind that children at different ages have different ways of understanding things. Every parent knows his or her child's level of maturity and comprehension, but you can use this information as a guide to what works best with different age groups.

When speaking with your children, use 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. I have very good doctors, 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.

Don't be surprised if a child between the ages of 5 and 8 is mainly concerned about himself. "Who will take care of me?"

is a common question. This is not because young children are selfish. 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. Older children also need to be reassured that their needs will be met.

Children above the age of 5 or 6 are likely to have more questions. Be prepared to answer their questions to the best of your knowledge, but keep in mind that there is no need to talk beyond what is asked. 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. 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 safer and more secure.

Ask professionals for guidance. If you need guidance before talking with your children or at any time afterward, contact Cancer Care. 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 your or a family member's treatment plan 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 Mom is in the hospital, who will take them to school, make dinner, or take them to after-school activities? Let your children know these concerns are important to you, too. If you don't have your support team (relatives, neighbors, and friends) in place yet, reassure your children that there will be a plan and that you'll let them know about it.

### Prepare children for possible treatment side effects.

Watching a loved one experience side effects can be upsetting to children. Chemotherapy and other medicines that destroy cancer cells 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, they can handle things better. With children aged 5 to 8, 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 aged 5 to 8, "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 radiation (treatment of cancer with high-energy rays that destroy cancer cells) 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 your continued love and caring for your children during a difficult time.

**Help children stay connected during treatment.** One way to help your children cope with cancer is to help them feel connected while a loved one is in treatment. 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. Letting your children know how much they are loved will make it easier for them to cope.

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 he or she was 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, he or she 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. But they shouldn't be expected to handle adult responsibilities, such as paying bills.

Let your children know that you are thankful if they want to 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 your children know that although you (or another family member) have cancer, it is not all that your family is about. Remind them often that no matter what changes the cancer might bring, your love for them will never change.

### **Talking About the Prognosis**

As with any discussion about cancer, consider the age of your children when talking about a loved one's prognosis—the long-term outlook for recovering from the illness. Give only as much information as needed. 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.

Try to watch out for any emotional changes in your children that might indicate they are stressed from worry. 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. Again, be hopeful. Your children will take their cues from you.

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, Cancer Care can help. We provide counseling and referrals to support services close to where you live.

# Special Considerations When Talking to Teens

The teen years are often difficult. Talking to your teenager about a cancer diagnosis, treatment, and prognosis might be one of your biggest challenges. This is because it is common for teens to be struggling with their own issues.

Teens are often very involved with their friends and school and may seem to put themselves first. This is because they 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 your 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 (close relatives or close family friends) they can go to, but let your teens decide.

**Strive for consistency.** Allow teens to spend as much time as needed 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 the parent or loved one who is sick or perhaps 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 "Will I get this cancer?" Check with your medical team about how to best answer these questions. In addition, your teen might be concerned about the cost of treating your cancer and wonder if there will be money for college or other big expenses. 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 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 brother or sister get better.

**Include siblings in what's happening.** Be available for any questions or concerns children in the family might have. Be honest and hopeful. If the child with cancer is in the hospital, siblings may want to draw pictures, send cards, and talk on the phone or visit. At home, find ways for the child with cancer and his or her 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 well children. Having a sibling with cancer is very emotional for well children. In addition to being worried about their sibling, your well children might 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.

## **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 Cancer Care 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



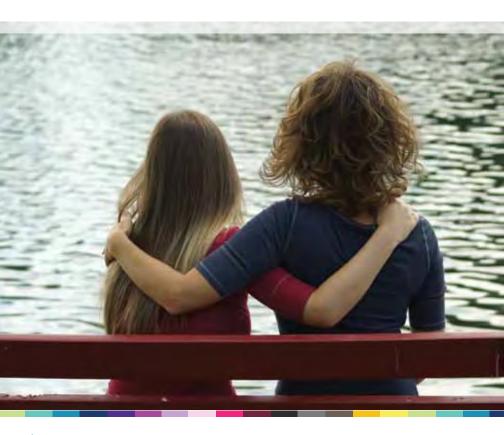
that cancer is only one of many things to talk about. Enjoy being together.

**Don't be afraid to ask for help.** Cancer*Care* provides free 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. Cancer Care and the resources listed on page 21 can help.



### More about helping children cope Frequently Asked Questions

• 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?

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 Cancer Care 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?

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.

### 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 more 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.

### 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 with certainty 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 awhile. 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, another person might help getting your children to school, and another might 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.

My teenagers want to meet my doctors and see
• the hospital. Is this a good idea? Are there support groups for teens?

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. Support groups for teens, such as those available through CancerCare, also make it easier for teens to feel informed and connected.

### Resources

### Cancer Care

800-813-HOPE (4673) www.cancercare.org

### **American Cancer Society**

800-227-2345 www.cancer.org

#### **Kids Konnected**

800-899-2866 www.kidskonnected.org

### **National Cancer Institute**

800-422-6237 www.cancer.gov

### SuperSibs!

888-417-4704 www.supersibs.org

#### BOOKS

### **Butterfly Kisses and Wishes on Wings**

By Ellen McVicker http://butterflykissesbook.com (2006)

### Can I Still Kiss You?

Answering Your Children's Questions About Cancer By Neil Russell Health Communications; Deerfield Beach, Florida (2001)

### 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 (1996)

### What About Me?

A Booklet for Teenage Children of Cancer Patients By Linda Leopold Strauss Cancer Family Care; Cincinnati, Ohio (1986)

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for Help and Hope, visit or call:

www.cancercare.org 800-813-HOPE (4673)