

FRANKLY
SPEAKING
ABOUT CANCER

What Do I Tell the Kids?

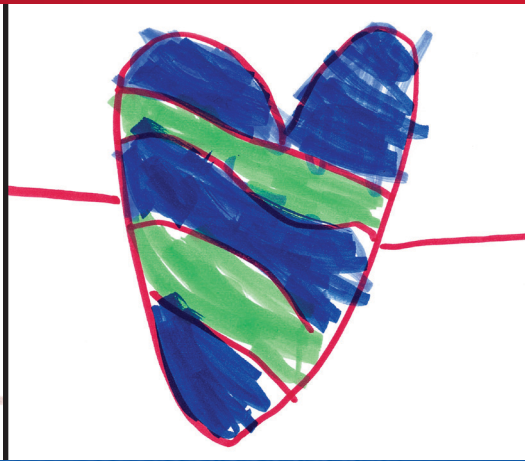


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Introduction

Cancer affects a family in many ways. Every family member's experience is unique and different, often making it hard to know how to provide support to one another. There are changes in day-to-day routines and more responsibilities to be managed. Feelings of anger, sadness, helplessness, regret and fear may touch different family members at different times, making life unpredictable for everyone.

When someone in the family has cancer, it is normal to focus attention on that person's medical treatment, and their well-being. Many parents try to protect their children by not sharing information about the situation. We don't often realize that even if they are not told about cancer, children of all ages can feel the impact of an illness on a family.

If you are a parent, or caring for a child and cancer is in your family, this booklet is meant to give you information about a child's general understanding of cancer, ways to talk to them about cancer, some common behaviors you may see in children, and ways to support your family through this experience.

ANY EMOTION IS OK. DON'T TRY TO BE PERFECT. FAIL A LITTLE, PREVAIL A LITTLE. GET THROUGH IT BEST YOU CAN.

— parent and lymphoma caregiver



"Support" by 5-year-old boy whose father is living with cancer.



What Kids Understand and Things You Might See

While they have no understanding of cancer, children as young as infants can feel the impact of cancer on a family. This section provides an overview of what children at different ages understand about cancer, as well as some common feelings they may experience and behaviors you might see.

Infancy-Toddlerhood

WHAT CHILDREN UNDERSTAND

No understanding of cancer

Able to sense changes in day-to-day routines

Aware of changes in behavior and feelings of those around them

COMMON BEHAVIORS & FEELINGS

More tantrums than usual

Changes in eating and sleeping habits

Separation anxiety: Difficulty separating from parents/caregivers (clingy)

**0-2
YEARS**

"Scribbles" by 2-year-old boy whose grandfather is living with cancer

Preschool

WHAT CHILDREN UNDERSTAND

Generally **have some understanding** of a simple illness like a cold, but may not have any experience with, or understanding of, a serious illness like cancer

“Magical thinking”: Thinking they did something to cause cancer (e.g., “I wouldn’t go to sleep and kept Mommy awake. She was very tired and I think I made her sick.”)



Artwork by 5-year-old boy whose father is living with cancer

3-5
YEARS

COMMON BEHAVIORS & FEELINGS

Regression: Acting younger than they are (e.g., suddenly wetting the bed even if they have been potty trained)

Short and intense **bursts of emotion**

Asking the same **questions** about cancer over and over again

Separation anxiety: Difficulty separating from parents/caregivers (clingy)

Playing or acting out themes related to doctors, sickness, etc.

School Age



Artwork by 7-year-old girl whose father is living with cancer

WHAT CHILDREN UNDERSTAND

Can usually understand there is a difference between a simple illness (e.g., cold) and a serious illness (e.g., cancer), but may not have had any experience with cancer

May have misinformation about cancer (e.g., may think cancer is contagious)

“Magical thinking” – thinking they did something to cause cancer (e.g., “I wasn’t behaving and when Mommy told me to stop I yelled at her and said some really mean things. I think I might have made Mommy sick.”)

**6-8
YEARS**

COMMON BEHAVIORS & FEELINGS

Regression: Acting younger than they are (e.g., baby talk or wetting the bed)

Worrying about the person living with cancer as well as others (fear that others will become sick)

Asking questions related to physical changes (e.g., hair loss, bandages, etc.)

Showing anger if normal day-to-day routine is changed because of cancer (e.g., if they can’t go to soccer practice because dad is too sick to drive)

Separation anxiety: Difficulty separating from parents/caregivers (clingy)

Playing or acting out themes related to doctors, sickness, etc.

Distancing themselves from the sick parent because of fear or discomfort

Middle School Age

WHAT CHILDREN UNDERSTAND

Often **have a basic understanding** of cancer (have usually heard of cancer and even know of someone who has had cancer)

May have misinformation about cancer (e.g., may think cancer is contagious or that everyone who has cancer dies)

“Magical thinking” – thinking they did something to cause cancer (e.g., “I haven’t been doing well in school and my teachers have been calling home a lot. It’s been making mom upset and I think all the stress made her sick.”)



COMMON BEHAVIORS & FEELINGS

Showing anger if normal day-to-day routine is changed because of cancer (e.g., if they can’t go to soccer practice because dad is too sick to drive)

Hiding feelings from family and friends

Worrying that others will become sick

Showing fear and sadness as anger, and often directing it at family members

Feeling embarrassed by the sick parent because they are different

**9-12
YEARS**

Artwork by
9-year-old girl
whose brother
died of cancer

Teens

WHAT CHILDREN UNDERSTAND

Likely to **have a basic understanding** of what cancer is; able to understand many of the medical aspects of cancer

May **have misinformation** about cancer (e.g., may think cancer is contagious)

May be **thinking more** about life and death/the meaning of life

COMMON BEHAVIORS & FEELINGS

Struggling between remaining close to family while also trying to gain independence as a teenager

Showing anger if normal day-to-day routine is changed because of cancer (e.g., if they can't go to soccer practice because dad is too sick to drive)

May not share feelings or talk openly with family or friends about the cancer experience

Taking out frustrations or anger on family members

13-18
YEARS

"Cancer doesn't change everything" by 15-year-old girl whose brother died of cancer





Talking About Cancer

Talking with your family about cancer can be very difficult. Parents often fear that having a conversation about cancer will scare their child and only make things worse. As a result, the topic of cancer is often kept from kids and talked about in whispers between adults behind closed doors.

CHILDREN NOTICE CHANGES

The fact is, even if your child does not know about the cancer diagnosis, they usually know something has changed. They can sense your feelings through body language and conversations overheard; they notice changes in day-to-day routines; and they may be observing physical changes in the person living with cancer (e.g., weight loss, exhaustion, hair loss). Often, if adults in the family are not talking openly, children will not feel comfortable asking questions about changes taking place. They keep their thoughts and feelings inside, often fearing the worst. By having a conversation with your child, you are letting them know that they are an important member of the family, and you are giving them permission to have and to express their feelings and ask questions.

“Feelings” by
9-year-old girl
whose grandparent
died of cancer

PREPARING YOURSELF

Before talking with your child, prepare yourself for possible questions or feelings your child might have. Also be aware of feelings that may come up for you during the conversation. While you may expect your child to be very emotional and have many questions, it may be more likely that they remain quiet and have very little response at the time. Let them know that if they have questions or want to talk later they can come to you then.



TIMING YOUR CONVERSATION

You know your child best, and you probably know the best times to have important discussions with them. It can be helpful to avoid having conversations when your child is hungry, tired, stressed, or when there could be interruptions (e.g. television, cell phones, email). While your talks will probably be short, it is best to time the conversation when you are not going to feel rushed. Depending on your child's comfort level with direct conversations, it may also be helpful to talk when direct eye contact is not required; for example, on a car ride or while playing basketball. Talking with your children in these situations may not put as much pressure on the child to respond immediately.

LANGUAGE

With a calm voice, try to use clear and simple words that state the facts. Using the appropriate words (e.g., cancer, chemotherapy, radiation) gives your child the language they need to think about and understand what is happening and ask questions. Children's books can also be wonderful tools for adults and children in finding the words to talk about cancer. These books don't have to be about cancer, but can be more generally about change, illness or loss. It can be helpful to check with a children's librarian at your child's school or the public library for suggestions.

I FEEL THINGS NEED TO BE APPROACHED DIFFERENTLY FOR DIFFERENT KIDS/PERSONALITIES. IT IS NOT A "ONE SIZE FITS ALL" THING EVEN WITH SIBLINGS. KIDS SHOULD NOT BE FORCED TO ACT, FEEL, ETC. A CERTAIN WAY.

—mother and breast cancer patient

PHYSICAL PRESENCE

Even when communication may feel strained and difficult, parents can help to create a comforting and secure environment just by remaining close by. Whether it is sitting quietly together, reading books, or being in the same room during homework time, your physical presence can send a message that you are here for them. Over time, this presence may generate more conversation about the illness.

66% OF PARENTS ANSWERING A CANCER SUPPORT COMMUNITY SURVEY SAID THAT THEIR CHILD(REN) DID NOT TALK OPENLY WITH THEM OR SHARE THEIR FEELINGS ABOUT CANCER.



"Love" by 7-year-old girl whose father is living with cancer

Some Key Points

Here are some things that can be helpful to share with children of any age. Tailor your message and language to your child's level of understanding and remember that even children of nearly the same age might need different language and have different questions:

CANCER IS NOT YOUR FAULT

It is common for children to think cancer is their fault; however, they generally will not share this with others. By explaining that cancer is not their fault, you can help your child to feel less guilt and stress around the cancer diagnosis.

ANY QUESTION IS OK

Children may be afraid to ask questions if they have not been given permission. Let them know that any question is ok, and that you will do your best to have an answer. There may be times that you don't know the answer, and that is okay too.

CANCER IS NOT CONTAGIOUS

Many children think cancer is contagious and become fearful of hugging or kissing their family member. Let them know it's ok to be close, and that they cannot catch cancer.



Common Questions and Tips for Answering Them

It can be helpful to prepare yourself for some questions that children commonly have about cancer. Whether or not these questions are being shared out loud, they are often on their minds. Think about possible answers so that you can be prepared if they do come up.

ANSWERING YOUR CHILD'S QUESTIONS

Below are some tips on answering common questions your child may have about cancer. How much information you provide may depend on your child's age. With younger children, it's usually best to give short answers with basic facts. As children get older, you may be able to offer more information. With kids of any age, you can provide the facts and then allow them to lead the conversation based on the questions they might have. Better to keep it simple and allow them to ask follow-up questions or share thoughts than to overwhelm them with information they may not be ready for or able to understand.

MY CHILDREN WOULD RATHER I COMMUNICATE OPENLY THAN TO LEAVE IT TO THE IMAGINATION. WHILE IMAGINATION IS GREAT, IN THIS CASE, KNOWING THE BAD RESULTS THAT CANCER CAN LEAD TO, THEY WOULD RATHER HAVE THE KNOWLEDGE.

— father and colon cancer patient

What is cancer?

To answer this question, you can start with the basic make-up of the human body. For example, “The body is made up of cells. Normally cells are healthy, but sometimes there are unhealthy, abnormal cells that grow and aren't supposed to be there. This is called cancer.” Once there is a basic understanding of cancer, you can go into detail on what part of the body is affected by the cancer (e.g., lung cancer).

Can I catch cancer?

Many children, even teenagers, think cancer is contagious. Because of this they may choose to distance themselves from the person with cancer. To help children understand, you can explain that cancer is not contagious like a cold or the flu. You cannot catch cancer. You cannot get it from hugging or kissing someone, or sharing their food or drink.

What is chemotherapy/radiation/surgery?

Cancer treatment can often seem like a mystery to children. You may go in for a treatment and come home feeling worse

because of the side effects. This can be very confusing for kids. When you talk to your child about treatment, try to include some information on possible side effects the doctor has shared with you. This can help prepare a child for what he or she may see in the future. Here are some possible ways to explain common cancer treatments and side effects:

“Chemotherapy is a medicine that attacks cancer cells. Chemotherapy is very strong and can sometimes cause the person taking it to feel sick and tired.” “Radiation therapy attacks cancer cells. It is similar to an x-ray and targets the area with cancer. I cannot feel radiation when it is happening, but it can cause me to feel tired afterwards.” “Surgery is when a doctor will surgically remove an area where cancer is located.” “Sometimes someone with cancer will have one type of treatment, and other times they will have a combination of treatments including chemotherapy, radiation, and surgery.”

Why are you losing your hair?

Hair loss is one of the most obvious side effects of cancer treatment. Many children think cancer causes hair loss and they don’t understand that it is actually the medicine that causes hair to fall out. One way to explain this is by talking about how the medicine is so strong that it attacks the normal cells at the same time as it attacks the unhealthy, abnormal cancer cells. Hair is made of normal, healthy cells, so sometimes people living with cancer lose their hair. Explain that eventually the hair will grow back (this is often something that children wonder about).

Do people with cancer die? Are you going to die? What is going to happen?

These can be the hardest questions to hear your child ask, and surely the hardest questions to answer. Your answers will depend on your personal cancer experience; however, many find it can be helpful to be hopeful and honest with your responses. Chances are your child will hear that other people have died from cancer, and perhaps they even

know someone who has died from cancer. One possible response may be, “People can die from cancer, but many people live. My doctors are doing everything they can to get rid of my cancer. That’s why I am at so many doctors’ appointments and have so many visits to the hospital. Right now they think that the medicine is working, but if that changes, I will let you know.” Children want to know that if there is a change, you won’t keep it from them. Try to update them when it seems appropriate.

Children also worry about what will happen to them if their parent dies. They wonder about who will take care of them and their basic needs. It can be very helpful and reassuring to let your child know who would take care of them, and remind them of the people in their life who care for them.

Can I talk about cancer with other people (friends, teachers, etc.)?

Some families may choose to make their experience with cancer very public, while others may choose to keep it private and only

share it with immediate family. Based on what the family does, children may feel very comfortable talking with others, or they may feel they have to keep it a secret. Even if your family chooses to be private, it can be very helpful for a child to have at least one or two other people they can talk to outside of their immediate family. This might be a friend, neighbor, teacher, or even someone in their extended family. Talk to your kids about some people in their life that they can talk with if they want to.

OPEN COMMUNICATION

Keeping your child informed, even if there have been no changes, lets them know that you are not hiding anything and you will include them when there are important things to report. Brief check-ins can be very comforting to a child.



Ways to Help Your Child

Opening up the lines of communication is a great first step in supporting your child. This includes sharing your feelings about cancer and encouraging your child to share theirs as well. Some other ways to help your child can include keeping your family's daily activities and routines as normal as possible. This means sticking to the rules of your family and encouraging their favorite activities.

TIPS AND TOOLS FOR HELPING YOUR CHILD

When looking for ways to support your child, here are some basic things you can do to help them through the cancer experience, both at home and in school.

Feelings

Once you begin talking with your child, you can begin to introduce tools that may help them deal with the cancer experience. Keep in mind that your child is probably looking to you on how to react and respond. If you share some of your feelings with your child, they may feel comfortable doing the same. It will also help them to understand that many feelings (e.g., anger, sadness, worry) are very normal when someone in the family has cancer. Expect that your child may have a range of feelings that may come and go quickly. It can be helpful to let them know any feeling is okay. For example, rather than saying “Don’t cry, it’s all going to be okay,” you might say, “It’s okay to cry, can you tell me about how you’re feeling?”

“Feelings” by 5-year-old boy
whose father is living with cancer

Routine

Try to maintain your family’s normal day-to-day life as much as possible. This may be very difficult, and you might want to ask for the help of family and friends. Encourage your child to continue with their favorite activities. These activities might end up being helpful ways for them to express themselves and allow them to have some normalcy when so many things in life are different. Allow for creative ways of expression (e.g., journaling, art, music, sports) that can be done as a family or individually.



Stick to the Rules

It's easy to stretch the rules when cancer is in the family to make up for what everyone is going through. Keep in mind, however, that this may be the most important time to stick to the rules. We put rules in place to keep our children safe and to keep their lives stable. By sticking to the rules, you can show your child that you will continue to keep them safe in a time when many things are out of control.

Allow Them to Help

Just as adults do, children may look for ways to help. If they show an interest in helping, you might suggest some small things they can do (e.g., making some food, cleaning up their room, making a card). Try to be aware, however, of how much a child is taking on, especially older children. It can be easy, and often necessary, to ask teenagers to share in the adult responsibilities (e.g., cooking, cleaning). Teenagers can take great pride in helping their family; however, taking on the

role of a parent can become very stressful. Try to find balance in a child's responsibilities and their need to just be a kid and take part in normal activities.

School

While cancer can be a very private family matter, sharing information with your child's school provides them with extra support when they are away from the home. You can ask your child who they feel most comfortable talking to at school and encourage them to check in with that person. Not only can the school provide support, but they can also let you know if they see any changes in your child. It is not uncommon for kids to start behaving differently in the classroom when cancer is in the family. Some common behaviors include: forgetfulness, sleepiness, poor concentration, irritability, hyperactivity, acting out, controlling behavior, and physical symptoms (e.g., headaches, stomachaches) resulting in frequent trips to the nurse's office.

Outside Support

Seeking outside support may be important if you notice behaviors in your child that concern you. Consider reaching out for help if your child is:

- **Showing extreme changes in behavior** (e.g., changes in eating or sleeping habits, severe mood changes, acting out)
- **Isolating themselves** at home and in school (e.g., child is withdrawing from friends and family)
- **Having difficulty at school** (e.g., their grades are dropping, they are misbehaving, teachers are reporting changes in personality or behavior)
- **Losing interest in activities** that used to be enjoyable
- Expressing **a desire to hurt themselves** or someone else *(In this case, find support immediately: contact your pediatrician, a local mental health center, or hospital)*

SUPPORT GROUPS CAN HELP

Even if your child is not showing any changes in behavior, they may find a support group or counseling to be very helpful. Being a child when cancer is in the family can be scary, isolating and confusing. Joining a group with other children going through a similar experience can help them to understand their feelings, and not feel alone.

WE WERE ABLE TO FIND A LOCAL SUPPORT GROUP FOR OUR GRANDSON. HE SAID HE CAN TALK FREELY TO THE PEOPLE AND CHILDREN THERE WITHOUT FEELING EMBARRASSED OR SELF-CONSCIOUS.

— grandmother and ovarian cancer patient



Resources

You do not have to do this alone. There are national and regional resources that are available to help you and your family.

RESOURCES

CANCER SUPPORT COMMUNITY (CSC)

1-888-793-9355

www.CancerSupportCommunity.org

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

CAMP KESEM

1-260-225-3736

www.campkesem.org

Camp Kesem is a network of college student-run summer camps and community groups for kids with a parent who has (or has had) cancer. The one-week sleepaway camps are a chance for kids ages 6-16 to have a fun-filled week, surrounded by other children who can understand their unique feelings, fears and concerns. There are over 60 camps across the country.

CANCERCARE

1-800-813-4673

www.cancercare.org

CancerCare offers telephone, online and face to face counseling, support groups, educational programs and publications.



"Follow your dreams" by 9-year-old girl whose brother died of cancer

KIDS KONNECTED

1-949-582-5443

www.kidskonnected.org

The mission of Kids Konnected is to provide friendship, understanding, education, and support for kids and teens who have a parent with cancer or have lost a parent with cancer. Kids Konnected provides support groups, summer camps, education, and fun events.

CHILDREN'S TREEHOUSE - CLIMB PROGRAM

1-303-322-1202

www.childrenstreehousefdn.org

The Children's Treehouse Foundation trains hospital staff to offer support groups for children whose parents have cancer.

Cancer Support Community Resources

Cancer Support Community's resources and programs below are available at no charge.

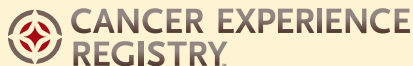
CANCER SUPPORT HELPLINE®



Whether you are newly diagnosed with cancer, a long-time cancer survivor, or caring

for someone with cancer, CSC's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Call Counselors available to assist you Monday-Friday from 9 am-8 pm ET. Our Call Counselors have been trained to answer your questions and link you to valuable information.

CANCER EXPERIENCE REGISTRY



The Cancer Experience Registry is designed to help people who have had a cancer diagnosis share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at www.CancerExperienceRegistry.org.

OPEN TO OPTIONS™



Free one-on-one treatment decision counseling is available with licensed mental health

professionals who help patients process information and formulate a list of specific questions for the oncologist. Appointments can be made by calling 1-888-793-9355, visiting www.CancerSupportCommunity.org, or by contacting an affiliate providing this service.

AFFILIATE NETWORK SERVICES

Nearly 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition and mind-body programs for people affected by cancer. For a full list of affiliate locations, visit www.CancerSupportCommunity.org or call 1-888-793-9355.

THE LIVING ROOM, ONLINE

"The Living Room" offers much of the same programming available at each CSC affiliate, online. You will find web-based support groups, discussion boards and social networking, a "build your own website" service, and educational materials for patients and caregivers. Join today at www.CancerSupportCommunity.org.

CANCER SUPPORT COMMUNITY

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 30,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.

www.CancerSupportCommunity.org | 888.793.9355

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The Cancer Support Community provides this information as a service.

This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professional to answer questions and learn more.

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