

# Parent Guidebook



**A Guide to Talking to Children  
about a Grown-up's Cancer**

**Angel  
Pack™**

# This book is for you.

**If you are a parent or caregiver who has been diagnosed with cancer, this guidebook is for you.** You may be experiencing a wide range of thoughts and feelings like anger, sadness, and fear. However, the biggest worry you may have is talking to the children in your life about your diagnosis. These are all very real and normal feelings.

This book will guide you in:

- How to tell children you have cancer.
- Age-specific fears and worries.
- Moving forward together as a family.

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# The importance of **TALKING TO CHILDREN** about cancer

- 1** Talking about cancer can seem overwhelming, but there is compelling evidence that being open with a child helps them cope. Research shows that children who are told about a grown-up's cancer diagnosis manage better than children who are kept in the dark.
- 2** If a cancer diagnosis is kept hidden, most children will suspect something is wrong. They will notice changes at home, such as less attention being shown to them, whispered conversations, and the adults around them seeming sad or upset.
- 3** If children suspect a serious problem they haven't been told about, they may make up their own explanation. Their thoughts and ideas may be scarier than the actual situation, and they might worry in silence.
- 4** Children can feel deeply hurt if they suspect or discover that they have been excluded from something important to them and their families. Sharing information shows you trust and value them.
- 5** Talking to children about cancer gives them a chance to tell you how they feel and lets them know it is okay to ask questions.

*Be patient with yourself  
and others, as it may take a few  
attempts before you find  
the best way to communicate during  
this challenging time.*

# PREPARATION

## Preparing for questions that might come up may help you feel more in control.

- Share the news with a few short sentences. Explain what you know so far and what will happen next.
- Assure them that they did not cause your cancer by anything they did or thought.
- Repeat information or say it differently when necessary.
- Ask your children what they know about cancer and then deal with any misinformation or myths (e.g., you can catch cancer like you might catch a cold or influenza).
- Ask them what they want to know about your cancer diagnosis.
- Only answer questions that the children ask.
- Don't assume they have the same fears as you.
- It is all right to cry; this teaches children that showing feelings is okay. But try not to overwhelm or alarm them with your reactions.
- Tell them they can come back to you anytime with questions, worries, and scary feelings.
- Don't make promises you can't keep. Rather than saying, *"I will definitely take you to the zoo,"* say something like, *"I hope I can take you to the zoo, but if I can't, it will be great to see the photos."*
- Tell the child you love them and reassure them they will always be cared for.

## BE PREPARED WITH BASIC FACTS

- The name of your cancer (e.g., breast cancer, lung, prostate).
- The part of your body cancer affects (e.g., stomach, bone, blood).
- How your cancer will be treated (e.g., surgery, chemotherapy, and/or radiation).
- Explain what cancer is in simple terms. Please see "Words to Help You Talk About Your Cancer" on pg. 18 of this booklet.

# PRACTICE

Here are some examples of discussion points for you to practice before speaking with a child.

Choose the level of complexity based on their age and ability to understand.

## TELLING THEM YOU HAVE CANCER

*"I have an illness called cancer. The doctor is giving me medicine to try and help me get better. The medicine might make me feel sick or tired some days, but I might feel fine on other days."*

*"I have cancer. It means some lumps are growing inside my body that should not be there, and they are making me sick. I am going to the hospital to have the lumps taken out. Then I will have some more medicine to make sure they do not grow back."*

## ADDRESSING MISUNDERSTANDINGS

*"Sometimes kids worry that they thought or did something to cause cancer. No one can make people get cancer."*

*"How do you think people get cancer?"*

*"We can still have lots of hugs. You can't catch cancer from me or anyone else."*

## EXPLAINING CHANGES AND REASSURING THEM

*"Mom needs to go to the hospital every day for a few weeks, so Grandpa will be taking you to preschool/school instead. He is looking forward to doing that."*

*"Dad is sick, so we may not be able to see him as much as we normally do. He loves you very much and wants to hear about all the cool things you are learning at school."*

*"I love your pictures, so maybe you can draw me some to take to the hospital."*

## ENCOURAGING FUTURE CONVERSATIONS

*"We can take more time later today, or you can write down any questions you might have or about how you are feeling and share them with me when you are ready."*

*"I am here for you. Let me know when you want more information."*

*"You might think of questions once I start my treatment. I want you to know that you can always ask me whenever you have a question."*

# Age-Appropriate SUPPORT AND ADVICE

## Preschool: 3 – 4-year-olds

Preschool-age children can understand basic concepts. However, they may not be able to fully understand the concept of cancer and may exhibit the following behaviors to cope with a difficult situation. It is best to be honest with them and talk about what is happening using short, simple phrases.

During this developmental stage, preschool children may:

- Return to sucking thumbs or wetting the bed.
- Become afraid of the dark, monsters, animals, strangers, or the unknown.
- Stutter or use baby talk.
- Become overly active or seem detached from things that used to interest them.
- Have separation anxiety, especially at bedtime and when going to school.
- Behave aggressively (like hitting or biting).
- Repeatedly ask the same questions.
- Have meltdowns or temper tantrums.

### Tips:

- Your preschooler is learning a new language every day and can have a logical conversation with you. By talking with them, you may be able to learn more about their thought process and what they understand about your illness.
- Tell them that cancer is not like catching a cold and explain that doctors are not sure why people get cancer.
- Schedule special one-on-one time together. This helps provide security and connection.
- Find a Child Life Specialist or Social Worker trained in child development to help your preschooler process their feelings and understanding of cancer.

### Ways to reassure your preschooler:

"Mommy has breast cancer. The doctor will give me medicine that could make me feel sick. It might also make me lose my hair, but you can help me pick out a pretty hat if it does."

"Even if I am not able to be with you, Grandma will always be here to take care of you."

"Even when Daddy doesn't feel that well, he can still give hugs and snuggle with you."

## School-age: 5-10-year-olds

Children are becoming more concrete thinkers, as well as being more reflective. They may want to know more details about your cancer and how it will be treated. This is a good age to invite them to come with you to a clinic or hospital visit and teach them about your experience.

During years 5-10 children may:

- Be more logical, but their thinking can also be very rigid.
- Begin taking pride in their work and seek recognition for their accomplishments.
- Learn to understand other people's perspectives, rules for social cooperation, and appropriate behaviors.
- Prioritize being with friends, and question their parents as their sole authority. This is very normal as they become more critical thinkers.
- Develop a sense of privacy and may not want to tell their friends about your diagnosis.

### Tips:

Use a friendly but firm communication style. Give them open and honest answers about your diagnosis and treatment.

- Reassure them that they did not do anything to cause your cancer.
- Keep children involved by giving them a special role or responsibility around the house or showing them ways to help care for the adult who is sick.
- Remember that your behavior serves as a model for children's behavior.
- Being honest with children will be especially helpful.
- Encourage school-age children not to feel guilty about enjoying activities and being with their friends. At this age, feeling guilty or ashamed are common responses to conflict and change.

### Ways to reassure your school-age child:

"Doctors who know a lot about cancer are going to take care of me and do everything they can to help me get better. If anything changes, I will tell you right away."

"When I am at the hospital getting medicine, Grandma will make you dinner, read you books, and tuck you in at night."

"You might see information about cancer from a friend. Please talk with me first if you have any questions."

## Preteen: 11–12-year-olds

Developing independence and responsibility is a key part of growing up, and preteens are doing their best to navigate this stage of life. Preteens go through dramatic emotional and physical growth, and experts often compare this development phase to being like a toddler again.

As they head toward their teen years, 11–12-year-olds may:

- Swing from being happy to being sad. They may cry and react intensely to a grown-up's cancer diagnosis.
- Feel embarrassed by your appearance.
- Ask if you will die and wonder who will take care of them.
- Not want to tell their friends about your diagnosis.

### Tips:

- Provide consistency with schedules and routines, which can help prevent mood swings.
- Allow children some personal independence.
- Encourage regular activities and guilt-free time with friends.
- Talk openly about death and dying and discuss worries and fears.

### Ways to reassure your preteen:

"I know you may not want to talk about my new diagnosis right now, but I think it's important for you to connect with someone. Is there someone you would feel comfortable talking to?"

"I have leukemia. It's a type of blood cancer. I will be very tired due to chemotherapy treatments, but I'll do my best to be there for you."

"We can still hug and snuggle. You can't catch cancer like you catch a cold."

## Teen: 13-18-year-olds

Emotional, intellectual, and social changes are common occurrences for teenagers. They will have a deeper, more mature understanding of their grown-up's cancer diagnosis. However, their growing independence may cause isolation and make it difficult for them to know what to do or how to react.

During these pivotal years, teens may:

- Understand and show greater capacity for caring, sharing, and developing deeper relationships.
- Be imaginative, enthusiastic, sensitive, impulsive, moody, and unpredictable.
- Experience anger, fear, guilt, and resentment due to a grown-up's cancer diagnosis.
- Spend less time with parents and more time with friends; often hiding their feelings from their parents.

### Tips:

- When talking with teens, try to ask inquisitive, not leading, questions.
- Listen to their thoughts about the future.
- Give them privacy when needed.
- Offer to connect teens with a counselor or school Social Worker for additional support.
- Encourage positive and safe ways to vent anger and frustration, such as journaling, exercising, or joining a teen group.

### Ways to reassure teens:

"I know we haven't been able to spend as much time together lately. Let's make sure we have one-on-one time every week. You are a priority to me."

"This can be a lot of information to take in. We can talk more after you have had some time to process what is going on with Dad's cancer diagnosis."

"You may be interested in some resources I've found. Take a look at this list of books that might be helpful."

# Community of SUPPORT

If children attend daycare or preschool or have a babysitter, this can be a place where they can be themselves when things are tough at home.

## **YOUR CHILDREN'S CARE PROVIDERS AND EDUCATORS**

- Tell the staff about your cancer diagnosis and ask them to keep you informed if your children's behavior changes.
- Let the staff know what the child has been told about your diagnosis, so they can consistently share the same information.
- Help the staff to understand that most young children would prefer not to think about their grown-up's illness any more often than necessary and encourage them not to talk about cancer unless children bring it up.
- Use the "School Communication Form" included in this parent care package to ensure the proper staff is informed.

## **YOUR CHILDREN'S FRIENDS**

- If children come to your house to play, it is helpful to make sure their parents understand what is happening and what their child is likely to see, hear, and experience when visiting your home.
- Discuss with the parents how they want questions answered if their child asks about your illness. Encourage the parents to let you know if their child expresses any concerns about spending time with you and your child.
- It is important for children to continue to have play dates if you can tolerate activity and a bit of noise. If it is difficult to have children play at your home, don't hesitate to accept offers for play dates at a friend's house.
- Prepare children for questions from their friends. They might hear, "*Why doesn't your mom have hair?*" or "*Why does your dad sleep on the sofa all day?*" You can help children figure out how to answer these questions.
- It is unlikely that preschool children will ask sensitive questions like "*Is your mom going to die?*" but encourage them to tell you if such tough questions arise.

# How to respond to YOUR CHILD'S EMOTIONS



**FEAR:** Some children will become fearful and worried. It can be hurtful if they start to fear you.

*Response: Explain that even though you have cancer, you are still the same person (especially if you look a bit different). Help children deal with their concerns by giving them a chance to talk about their fears.*



**ANGER:** It is natural for children to feel angry about your diagnosis as it is likely to change their routine. When children don't know how to cope, their fears can be channeled into anger because it is a more familiar response.

*Response: An angry outburst can be a chance to find out what is happening. Try not to react. Instead, remind them that they can talk to you anytime about how they are feeling.*



**TEARFUL:** Crying is a natural response when children hear someone they love has cancer.

*Response: If your children cry, assure them it is okay to do so and that it is a natural reaction.*



**EMBARRASSMENT:** Even if your family talks openly about it, many children will not want their friends to know about your cancer.

*Response: Let them know you understand they may not want to share information about your illness with others. If your appearance changes, talk to them about how they feel about it.*



**NO REACTION:** Sometimes, children appear not to have heard the news or do not react. You may be confused or hurt by this, especially if it takes some courage to talk about it. This reaction is not unusual often, children are protecting themselves and need some time to digest the information.

*Response: Remind them that they can talk to you anytime about what is going on.*

# Ways to **SUPPORT YOUR CHILD** during treatment

1

## **MAINTAIN ROUTINES WHEN POSSIBLE**

- Keeping life normal for children during treatment can be difficult to do when you are coping with the changes that cancer brings.
- If something does need to change, explain what they can expect and how it may affect their schedule. Provide simple explanations for unfamiliar situations.
- Stick to their routine as much as you can. For example, try to continue or develop bedtime rituals that can help ease their worries and fears.
- Continue usual discipline and limit setting.

2

## **BE RECEPTIVE TO QUESTIONS AND EMOTIONS**

- Listen and be alert to their feelings, which they may express through speech or play.
- Focus on each day and expect good and bad days for both adults and children.
- On the days when you can't cope with much, let them know, rather than protect them from the reality of how you are feeling.
- It is normal for children to think mostly of themselves. Even when you don't feel well, they may be more concerned with how it affects them. You may find this reaction hurtful or frustrating, but it is normal.
- Help children identify their feelings.

# 3

## **PROVIDE OPPORTUNITIES FOR BUILDING COPING SKILLS**

- Give children lots of opportunities to play. Their play may reveal worries or fears.
- Let them get physical activity every day to get rid of anxiety and to provide an outlet for any aggression.
- Most children will want to help at home during treatment. If they feel they are being helpful, it can increase their confidence and self-esteem because it shows that you trust, value, and need them.

# 4

## **SET ASIDE TIME FOR ONE-ON-ONE ATTENTION AND FUN!**

- Organize times for children to tell you about their achievements each week.
- Organize special activities (when you are feeling up to it).
- Think of things to do that don't require much energy. You may want to read to them or watch TV together.
- Plan for "cancer-free" activities with family or friends that allow you to laugh, joke, and relax.
- Let them know that it is still all right to have fun.

# Talking about **TREATMENT**

Children often need information to prepare them for what is happening to a person with cancer. Understanding your treatment, why and how it is done, and potential side effects, can help them cope. What they will need to know will depend on their age.

- Let your children be your guide as to how much they already understand and how much they want to know about treatment.
- Keep them up to date with how long treatment will take and how long you might be in the hospital.
- Explain who will be taking care of them and who will be doing specific tasks while you are away.

## **EXPLAINING SIDE EFFECTS**

It is important to prepare children for any side effects of your treatment. For example, tell them about any physical changes that might occur, like losing your hair. Also, tell them about emotional changes you may feel. Explain that you might be a bit grouchy or irritable, but that it is not their fault.

Reassure them that even if your appearance changes, you are still you.

Young children need less information than older ones. They are also more likely to be confused by the information they are given. They may be able to repeat back to you what you told them, but still not understand it.

It can help to give children some time each day to ask questions, such as bedtime or during breakfast. Again, you may need to repeat explanations multiple times before they begin to understand.

Explain to them that the side effects are separate from the cancer symptoms. It is common for children to get upset on chemotherapy days when they see the effects of the drug, such as fatigue or vomiting, because they may worry that the cancer is getting worse.

Let them know that if there are no side effects, it does not mean the treatment is not working. Explain to them that changes to your weight and hair will return to normal after treatment.

# Hospital and CLINIC VISITS

You might worry that children will get anxious if they see you in the hospital or having treatment, but it can be frightening if they are separated from you and can't picture where you are.

Ask them if they want to go to the hospital or the treatment clinic. If they are scared, they might feel guilty and make excuses to avoid going. If they seem anxious, rather than try to persuade them, let them know they are welcome to come if they change their mind.

If they do want to visit, and you can arrange it, have a plan to help the visit go smoothly.

## TIPS FOR VISITS

- Before they enter the room, tell them what they may notice: the equipment, different smells, and noises (e.g., buzzers, beeps), and how different patients may look (e.g., tubes, bandages, IV drips).
- Keep the initial visits brief to allow them to become familiar with the hospital or clinic environment.
- Give children specific jobs or activities to do during the visit. They may want to help by getting you a drink or magazine from the hospital gift shop.
- Help them understand that they might feel more emotional or experience new emotions during the visit. Explain the kinds of emotions, like fear or sadness, that people sometimes experience when they visit the hospital.
- If children are reluctant to go to the hospital, their first visit could just be to the visitor's lounge, café, or restaurant. Reassure them this is okay and that they can send a card or call if they prefer.
- Get them to bring art materials, books, or toys to keep them occupied. See if you can use Zoom™ or FaceTime™ on a cell phone to communicate with your child.
- After the visit, talk to them about how they felt.
- Ask the staff for help. Nursing staff and Social Workers are sensitive to children's needs during this tough time and can offer support to your children if necessary.

# Navigating Questions about Death

This is the question that most parents fear more than any other. It is natural to want to reassure children that there is nothing to worry about, but no one can promise that a person will not die.

All children learn about death. Their questions and concerns about dying may come up at any time after discussing your cancer diagnosis.

All children, except very young ones, wonder if having cancer means you are going to die, even if they don't ask the question aloud. They may be afraid to ask you about death and dying.

A child's imagination about what happens when someone has cancer is often worse than reality. So, if adults change the subject or remain silent, they will sense that it is not acceptable to talk about death.

You can explain to your child that when someone dies, they will be physically gone, and that the child will no longer see them. This conversation may need to be repeated several times because children will continue to have questions.

It is worth knowing that the question "Are you going to die?" often doesn't mean what you think. For example, younger children may really mean, "Who is going to look after me?". Older children may wonder, "Can we still go on our vacation?". Try to explore the question by asking, "Do you have something you're worried about?" or "What is it you are thinking about?".

Some children think that everyone with cancer dies, so it is good to explain that many people get better through surgery and medicine, and that new treatments are being discovered all the time.

How specific you are about the likelihood of death depends on your circumstances.

## Some answers to practice with:

"We don't expect that to happen, but I'll probably be sick for a while. Sometimes it makes me sad, and I wonder if you get sad, too."

"Some people do die from the type of cancer I have, but I'm going to do everything that my doctor suggests to get better."

# TAKING CARE of Yourself

It is important to stay healthy and focus on taking care of yourself. Stress can cause you to feel frustrated, anxious, or even make it easier to catch a cold. Find ways to unwind and refocus your energy, even if you start with just five minutes a day.

## **BE CREATIVE:**

- Write in a journal.
- Doodle or draw.
- Work with clay to reduce negative mood and anxiety.
- Create a collage to express your feelings.
- Take photos of friends, family, and life around you.

## **GET PHYSICAL:**

- Try light weightlifting.
- Go for a walk.
- Practice yoga.
- Enjoy a leisurely bike ride.
- Do some light stretches.

## **RELAX:**

- Practice breathing techniques to help lower stress.
- Allow time for 8-10 hours of sleep each day.
- Listen to soothing music.
- Try essentials oils such as lavender to relieve stress or sweet orange to help brighten your mood.
- Take a warm bath or shower.

## **WHO IS YOUR SUPPORT SYSTEM?**

It is important to know who to go to for help when you are feeling too sick to do certain tasks. There are people around you who would be happy to lend a helping hand.

## **WHO CAN YOU ASK FOR HELP?**

- Family and friends.
- School teachers.
- Nurses.
- Counselors.
- Spiritual leaders.

## **CLINICAL RESOURCES:**

- Social Workers.
- Patient Navigators.
- Oncology therapists.
- Registered Dieticians.
- Chaplains.

As you navigate the changes that your cancer diagnosis has brought into your life, be kind to yourself, and know that you are not alone.

**For more resources, visit us at [www.mnangel.org](http://www.mnangel.org).**

# A Child-friendly GLOSSARY

Words to help you talk about your cancer.

**ANESTHETIC** – A medicine that makes a person not feel any pain when they have an operation.

**BENIGN** – Not cancer.

**BIOPSY** – When the doctor looks at cells in the body to see if they are healthy or not.

**BLOOD COUNT** – A test that checks how healthy the blood is.

**BONE MARROW** – The soft, spongy jelly inside bones where different blood cells are made.

**BONE MARROW TRANSPLANT** – Replaces damaged bone marrow with healthy bone marrow to help the person with cancer get better.

**CANCER** – Cancer is an illness that makes some cells stop working properly.

**CELLS** – The body is made up of millions of tiny things called cells, and each has a job to make your body work and stay healthy.

**CENTRAL LINE** – When a person has a tube in their body, they don't have to have medicine given by a needle.

**CHEMOTHERAPY** – Special medicine that destroys cancer cells.

**CT SCAN** – A test that makes pictures of the inside of your body to help doctors see what is going on.

**DIAGNOSIS** – When the doctor identifies what is making someone sick.

**DONOR** – A person who gives someone else blood or another part of their body.

**HEMATOLOGIST** – A doctor who treats people whose blood is making them unwell.

**IMMUNE SYSTEM** – The part of the body that helps someone stay healthy by getting rid of germs inside the body. It fights illness if somebody does get sick.

**IMMUNOCOMPROMISED** – When someone gets sick very easily.

**INTRAVENOUS (IV)** – Putting a needle into a vein (where blood is in the body).

**IV POLES** – Tall poles with hanging bags of medicine that a person will receive. The pole is attached to a machine that knows how much medicine to give.

**LYMPH NODES** – Lymph nodes are like filters that remove germs that could harm you. Sometimes, germs can cause some of the lymph nodes to swell.

**MALIGNANT** – Means cancer.

**MEDICAL ONCOLOGIST** – A special doctor who uses strong medicine to treat people.

**METASTASIS (ADVANCED CANCER)** – When the cancer cells have travelled to another part of the body.

**MRI SCAN** – A way to take pictures of the inside of a person's body to see if they are sick.

**NAUSEA** – Feeling sick in the tummy.

**NEUROLOGIST** – A special doctor who treats people with cancer in the brain.

**PALLIATIVE TREATMENT** – Sometimes, the doctors and nurses can't stop the cancer from growing, and they will give the person medicine to make them feel better and stop any pain.

**PORT-A-CATH** – A tube (port) placed inside the body to receive medicine.

**PROGNOSIS** – What the doctors think might happen after treatment and someone's chances of getting better.

**RADIATION** – Invisible high-energy rays (often x-rays) that go into the body to destroy cancer cells and make the cancer smaller.

**RADIATION ONCOLOGIST** – A special doctor who treats people who have cancer using high-energy rays, usually x-rays.

**RECURRENCE/RELAPSE** – When cancer comes back, and the person feels sick again.

**REMISSION** – When cancer goes away after treatment.

**SIDE EFFECTS** – Problems that can make someone feel sick or tired or lose their hair after treatment. Someone might gain or lose weight or experience other changes.

**STAGE** – The term a doctor uses to explain how serious a cancer diagnosis is.

**SURGERY** – When someone has an operation, and a surgeon removes the cancer.

**SYMPTOMS** – What people feel (e.g., sore, itchy) or see (e.g., redness, a lump) when something is not right in the body.

**TUMOR** – A lump in the body that should not be there.

**ULTRASOUND** – A test that allows doctors to look inside the body to find out if anything is wrong.



This book is a part of the Angel Pack™ kit for children ages 4 to 18.  
Angel Packs™ are filled with tools to help families discuss cancer  
in an age-appropriate and comforting way.  
Angel Packs™ are meant to assure families impacted by cancer  
that they are not alone.

For more information about Angel Packs™ please visit [www.mnangel.org](http://www.mnangel.org).

