FACING CANCER *together*

A Guide for

Parenting through Cancer

angel foundation

This book is for you.

If you are a parent or caregiver who has been diagnosed with cancer, this guidebook is for you.

This book will help you explore and learn more about what it means to be a parent or caregiver with cancer. You are probably experiencing a wide range of thoughts and feelings like anger, sadness and fear. However, the knowledge that you have children and need to talk to them about your diagnosis is probably the biggest worry. These are all very real and normal feelings. *You are not alone.*

This book will guide you in:

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

Contact Emily Rezac if you would like more information or advice.

erezac@mnangel.org (612) 627-9000

You've Just Learned You Have Cancer

So, here you sit with a frightening, life-changing diagnosis of cancer. Your world has been rocked with sudden demands on your time and body. On top of that, there is the fact that you have a family to care for. You are still a parent or caregiver, despite your cancer diagnosis. You have primal instincts to protect your children and put their needs first.

This guidebook, provided through Angel Foundation's Facing Cancer Together program, is designed to teach you how to care for yourself, as well as your family's health and wellbeing, by communicating simply and honestly.

The thought of having to tell your children you have cancer can be overwhelming. You may want to shield your child from worry or feel concerned that you won't be able to answer their questions about your diagnosis, treatment or even questions about death.

Cancer is a complex illness and talking about it can feel challenging. You may stumble. You may take a few steps backward. **That is okay.** There is no perfect way to tell children that you have cancer, but they do need to know.

This guidebook can help you prepare yourself to have the difficult (yet open, honest and loving) conversation about how your family can face this cancer diagnosis together.

Step 1

Prepare for Conversation

Organize your thoughts and feelings before telling your children. It is best to tell them yourself, or if you are unable to, choose a close relative the children trust. Be open, honest and prepared to say out loud, "I have cancer."

Timing

To be prepared for questions that might arise, wait until you know all the facts about your cancer diagnosis and treatment plan.

- Share this information soon after your treatment plan is in place.
- Focus all your attention on this important conversation.
- Allow enough time to answer questions.

Step 2

Conversation

Find a quiet time when your child isn't tired or distracted with other activities. Take a few deep breaths and know that telling your child, openly and directly, will help build trust between the two of you.

Possible Conversation Starters

"Do you have some time to talk about something important?"

"I'd like to share some important news with you."

Be Prepared with Basic Facts

- The name of your cancer (e.g. breast cancer, non-hodgkin's lymphoma).
- The part of your body the cancer affects (e.g. stomach, bone, breast, blood).
- How the cancer will be treated (e.g. surgery, chemotherapy, and/or radiation).

Important Information to Share

- "We don't know why I got cancer."
- "It is not contagious."
- "It is not your fault."

How to Answer the Difficult Question, "Will you die?"

"If I find out any new information or anything changes, you will be the first to know."

"Right now there's not a lot known about the kind of cancer I have. But, I'm going to give it my best and do everything I can to get better."

Don't Be Surprised

- Your school-age child may only respond briefly. Developmentally, younger children tend to cope more positively and show emotions later on in different ways.
- Your teen may not want to talk for a long time about your diagnosis. Validate their feelings, but let them know they can still ask questions.

Additional Phrases to Consider:

"We can take more time later today or when you are ready."

"I'm here. Let me know when you want more information."

Step 3

After Your Conversation

Continue to keep lines of communication open and offer opportunities to talk about thoughts and feelings.

- Put one-on-one time with each child on the calendar. Individual attention will allow more opportunities for questions and discussion.
- Ask ongoing questions to see what your child understands about your cancer and treatment plan.
- Include your child in clinic appointments so they can learn about how treatment affects you. This will help clarify misunderstandings that may occur.

What If Relapse or Recurrence Occurs?

Relapse or recurrence may often mean more treatment. Talk with your children about the new plan and try to be open and honest with your feelings. Your children may ask if you might die. This is a very normal question to ask when someone is sick. You may want to consider responses like these:

"It's not happening to me right now, but if something changes, I will make sure you and the whole family understand what is going on."

"It all depends on how I respond to my treatment. Let's give that a chance to work. It worked before, so hopefully it will work again."

"It's okay to worry about this question, but let's try and live each day to its fullest. As a family, we can help each other put aside our worries."

Age-Appropriate Support and Advice

Preschool: 3-4 year olds

What to expect:

Have you noticed your child is growing up? Preschool-age children can understand basic concepts, especially being sick. They may not be able to entirely understand the concept of cancer, but be honest with them and talk about it using short, simple phrases. Your child may:

- Have potty accidents.
- Start speaking in baby-talk or regress in speech.
- Hit or bite when feeling frustrated.
- Think they can catch cancer. Be reassuring: preschool-age is still very self-centric.

Tips:

- Your preschooler is learning new language every day and can carry on a logical conversation with you. Talk with them and 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 a cold and explain that doctors are not certain why people get cancer.
- Schedule space on the calendar for special one-on-one time together. This helps promote love and connection between parent and child.
- Find a Child Life Specialist or Social Worker trained in child development to help process through your preschooler's feelings and understanding of cancer.
- **Angel Foundation offers one-on-one phone consultations. Please call for more information or additional advice for preschoolers.**

Ways to reassure your preschooler:

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

"Even if mom or dad are unable to be with you, you will always be taken care of."

For advice about infants and toddlers, visit our website:

https://mnangel.org/resources/

School-Age: 5-10 year olds

What to expect:

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

- This age group can grasp more logic, but their thinking can also be very rigid.
- Children at this age begin taking pride in their work and seek recognition for their accomplishments.
- School-age children are learning to understand other people's perspectives, rules for social cooperation and appropriate behaviors.
- Being with friends is becoming increasingly important and they may dismiss parents as sole authority. This is very normal as they are learning to become critical thinkers.
- School-age children begin to develop a sense of privacy and may not want to tell their friends about their parent or grandparent's 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 nothing to cause your cancer.
- Keep your child 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 your child's behavior.
- Being upfront with your child will go a long way.
- Encourage school-age children to feel guiltless about enjoying activities and being with their friends. At this age, feeling guilty or ashamed are common responses to conflict and change.
- **Angel Foundation offers a variety of programs for children, including summer camp, family retreats and fun group activities where your child can learn more about your treatment through play. Please call for more information.**

Ways to reassure your school-age child:

"You might look cancer information up online or hear something from a friend. Please talk with me first if you have any questions."

"A lot of people get cancer. The doctors know how to treat it and hope I will get better. If anything changes, I will tell you right away."

Preteen: 11-12 year olds

What to expect:

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

- It's normal for preteens to swing from being happy to being sad. Your preteen child may cry and react intensely about your cancer diagnosis.
- Preteens may feel embarrassed by their parent or grandparent's appearance.
- Your preteen may ask if you will die and wonder who will take care of them.
- Your preteen may not want to tell their friends about their parent or grandparent's diagnosis.

Tips:

- Provide consistency with schedules and routines, as this will help prevent possible mood-swings.
- Allow your child some personal independence. Encourage regular activities and guilt-free time with friends.
- Talk openly about death and dying and discuss worries and fears.
- **Angel Foundation offers a variety of programs for preteens, including summer camp, family retreats and fun group activities where your child can learn more about your treatment through play. Please call for more information.**

Ways to reassure your preteen:

"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."

"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. Do you have a friend or a teacher you can talk with?"

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

Teen: 13-18 year olds

What to expect:

Emotional, intellectual and social changes are common occurrences for teenagers. They will have a deeper, more mature understanding of their parent or grandparent'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.

- Teens go through less conflict with adults, but a new diagnosis may cause anger, fear, guilt and resentment.
- Teens understand and show greater capacity for caring, sharing and developing deeper relationships.
- Teens tend to spend less time with parents and more time with friends; often hiding their feelings from their parents.
- Teens can be imaginative, passionate, sensitive, impulsive, moody and unpredictable.

Tips:

- Talk to your teen and ask curious, not loaded, questions.
- Listen to your teen's thoughts about the future.
- Give privacy when needed.
- Offer to connect your teen with a counselor or school Social Worker for additional support.
- Encourage positive and safe ways to vent anger and frustration, such as journaling, exercise or joining a teen group.
- Angel Foundation offers a variety of programs for teens, including summer camp, Teen Outreach activities and expressive arts groups. Please call for more information.

Ways to reassure your teen:

"I know you are feeling frustrated or resentful of your extra responsibilities. Let's keep communicating and discuss how we can all help each other."

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

Typical Fears and Worries

The cancer experience impacts the entire family: you, your spouse or partner, children and your extended family. Each family will have its own way of facing this challenge. What this experience means to children may vary depending on their age, personality or temperament. The way your family has communicated together prior to your cancer diagnosis will highly impact how your child will react.

- **Children of all ages often wonder what this diagnosis means for them.** When big changes happen, a child's immediate thoughts turn to their basic needs. Who will take care of them? Who will feed them? Who will take them to soccer? Reassure your children that they are loved and not alone. Let them know you will make plans to take care of them no matter what.
- **Information brings families together.** Children are resilient and can handle information about your cancer diagnosis, treatment and prognosis. Provide your children with simple, honest and age-appropriate explanations to help ease their uncertainty and anxiety. Giving your children accurate information they can understand will also create a sense of trust and safety.
- **Create an open door for ongoing discussions.** Let your children know you are willing to talk about whatever is on their minds; and be prepared to listen. Assure them it is okay to share their full range of feelings. This will not be a single conversation, so remember to check in regularly with your children to see what they understand or if they still have questions. Asking them how they would explain your diagnosis to someone else might help reveal any misunderstandings. For children ages 2-8, learning through play is often helpful. **Angel Foundation offers a variety of programs where your child can learn more about your treatment through fun, hands-on activities.**
- Most children worry that their parent might die. Some children may ask directly, but others may not know how to ask about it; or they simply will not ask, as a means of protecting you. Create an opportunity during your conversations to ask them what their thoughts are.

"I learned that many children wonder if their parent might die from cancer. What do you think about that?"

"Have you ever worried about me dying?"

- **Communicate honestly about changes in your health, as soon as you are able.** Building a foundation of trust throughout your treatment will give you the opportunity to prepare and update your children if your treatment changes. Prepare them for the changes you expect and reassure them you will do your best to keep them informed of any other changes as they occur.
- **Maintain daily routines as much as possible.** With cancer treatment, your daily routine will most likely change. A daily routine provides predictability and security to children, and they may respond negatively with even a small shift in their routine. Reassure your child that someone will always be there to help them with meals, homework and getting to extra-curricular activities. You may not be able to control everything, but if the intention and awareness of routine is there, the rest will be manageable with the help of your support system.
- **Find time for your children to meet other children who have a parent with cancer.** Having a parent with cancer can be isolating. Being with other children in age-appropriate peer groups can help normalize their experience and help them feel less alone. **Angel Foundation offers a variety of fun programs that give children the ability to express themselves in a safe environment. These programs also help promote ongoing healthy communication and self-expression.**

Talk About Your Treatment:

Typically, everyone's treatment is different. It can include surgery, chemotherapy, radiation or all of the above. The following definitions can help you explain your treatment to your children. We encourage you to add your own words to these definitions.

- **Cancer** – *"Your body is made up of **cells**. These cells are super tiny and you need a microscope to see them. Cancer happens when cells that are not normal grow very fast and **do not know when to stop.**"*
- **Tumor** – *"When a clump of abnormal cancer cells group together, they form **tumors** that can take over and destroy surrounding healthy cells. This can cause my body to become very sick."*
- **Surgery** – *"This is the removal of a tumor. A surgeon will operate to remove the tumor and surrounding cells from inside my body."* Let your children know that you will not be awake for this procedure.
- **Chemotherapy** – *"This is strong medicine that targets and destroys abnormal cells. This medicine can be given in a pill, injection or through a port (see **Port-a-Cath**). This medicine will only be given to me for short periods of time, so my body can recover after each treatment."*
- **Radiation** – *"This treatment uses high-energy rays that shrink or destroy cancer cells. It may be given outside my body through a machine or radioactive material placed inside my body near the cancer cells."*
- **Port-a-Cath (Port)** – *"This tube is surgically placed, typically in the chest. It is accessed by a port needle during my treatment or when blood draws are needed. It is easier and less painful than an IV or finger pokes. Numbing cream can be used to help dull the poke sensation."* Ask your children if they would like to see what your port looks like.
- **Bone Marrow Transplant (BMT)** – *"All of our bones have spongy tissue inside them called bone marrow. A Bone Marrow Transplant is a procedure where healthy cells are gathered from either a donor or my own bone marrow. These BMT cells are used to help replace diseased cells with healthy, non-cancerous cells."*

Treatment Side-Effects:

There is no getting around it: side-effects from treatment stink! It is important to teach your children about possible side-effects so they feel prepared if you experience them.

Common treatment side-effects:

- Hair loss
- Weight changes
- Nausea
- Feeling tired
- Mood changes

Let your children know you have an important group of medical professionals to help you, and they each play an important role. Encourage your children to get to know who is helping you.

Your care team:

- Doctors
- Nurses
- Nurse Coordinators
- Social Workers
- Chaplains
- Nutritionists
- Physical/Occupational Therapists

What Does Cancer Mean for Me and My Family?

Life tends to change dramatically when cancer is a part of your family's story. From this moment forward, life will never be exactly as it was before. No family is the same; every family will respond to cancer very differently. How do you think you and your family will handle the next few steps?

A lot of these changes can be difficult to deal with and you may feel like you don't have any control. Life is hard enough right now with your illness, and adding the stress of caring for your children can sometimes feel like too much to handle.

Give yourself permission to ask for help around the house. Ask your spouse or partner to pitch in, or request your children's help with more chores or babysitting the younger children. These changes can be hard and you may feel guilty. However, you may find that asking for extra help shows your family that you trust them with additional responsibility and it can help bring your family even closer together.

Be mindful of your spouse or partner's needs, too. Encourage them to carve out personal time as they are now adding the role of "caregiver" to their plate. Taking up a hobby or finding a support group, **such as Angel Foundation's Caregiver group**, may be the medicine they need to recharge their batteries. This will help them be present and support you and your family with coping or emotional needs.

Be Mindful of Everyone's Mental Health

You will have your ups and downs throughout your treatment. Your moodiness or irritability might increase as you worry about how to handle treatment in addition to caring for your family. Remember that your family members may all be experiencing similar feelings.

It is normal for you and your family to feel:

- Lonely
- Sad
- Angry
- Afraid
- Confused
- Frustrated

It is common for both children and adults to hide their feelings in an attempt to protect those they love. However, this often causes more frustration and loneliness. The most important thing is to try and have those uncomfortable (but honest) conversations together. This can be a slow process for a family, but you might be surprised how much better you feel after you talk.

Angel Foundation offers a variety of fun programs to help families get the conversation started. Please call for more information.

Taking Care of Yourself

It's important to learn how to stay fit and focus on "self-care," which means focusing on you. Stress can cause you to feel frustrated, anxious or even make it easier to catch a cold or flu. Find ways to let off steam and refocus your energy.

Be creative:

- Write in a journal
- Doodle or draw
- Make your own art
  - Use clay when feeling upset or angry
  - Create a collage to try and express your feelings when words aren't enough
- Take photos of friends, family and life around you

Get physical:

- Light weight-lifting
- Go for a walk
- Do yoga

Relax:

- Learn breathing techniques
  - Practicing breathing exercises is proven to help lower stress
- Get enough sleep (8-10 hours) each day
- Listen to soothing music
- Try essentials oils
  - Lavender – known for calming and relieving stress
  - Sweet Orange – to help brighten mood

Who is Your Support System?

It is important to know whom you can go to for help (or ask questions of) when you are feeling too sick to help your child. There are probably many people around you who are more than willing to lend a helping hand.

Who can you ask for help?

- **Angel Foundation**
- Family and friends
- School teachers, nurses or counselors
- Spiritual leaders

Clinical resources:

- Social Workers
- Patient Navigators
- Oncology Therapists
- Chaplains

Resources

Additional local and national resources:

Angel Foundation
mnangel.org

Gilda's Club Twin Cities
www.gildasclubtwincities.org

Jack's Caregiver Coalition
www.jackscaregiverco.org

KidsHealth
www.kidshealth.org

Kids Konnected
www.kidskonnected.org

American Cancer Society
www.cancer.org

Books:

Preschoolers

Someone I Love is Sick: Helping Very Young Children Cope with Cancer in the Family by Kathleen McCue

A customizable book that tenderly addresses all stages of the cancer diagnosis including diagnosis, treatment, hospitalization, recurrence and end of life.

School-Age Children

Let My Colors Out by Courtney Filigenzi

For preschoolers and younger elementary-aged children. Colors are incorporated into the story to express a young boy's emotions as his mother goes through treatment for cancer.

The Hope Tree: Kids Talk about Breast Cancer by Laura J. Numeroff and Wendy S. Harpham

For elementary-aged children. Kids (age 5-12 years old) share their feelings, questions and experiences about having a parent who has cancer. This story can be used to address all types of cancer.

Mom Has Cancer! by Jennifer Moore-Mallinos

For younger elementary-aged children. A story about a little boy's mother who is diagnosed with cancer and the questions and conversations that come with the diagnosis.

The Rainbow Feelings of Cancer: A Book for Children Who Have a Loved One with Cancer by Carrie Martin and Chia Martin

For elementary-aged children. Through illustrations and text, children share feelings, thoughts and questions about their parent who has cancer.

Preteens

Butterfly Kisses and Wishes On Wings by Ellen McVicker

A resource about how to talk to a child about a parent's cancer diagnosis.

Because...Someone I Love Has Cancer by American Cancer Society

A creative art activity book for children to discover inner strengths and enhance self-esteem during a challenging time.

Teenagers

Brushing Mom's Hair by Andrea Cheng

A 15-year-old girl uses connected poems to express her reactions and feelings about her mother's breast cancer diagnosis.

My Parent Has Cancer and It Really Sucks by Maya and Marc Silver

This handbook aims to support teens through the difficult experience of having a parent with cancer.

Love Sick: Teens Reflect on Growing Up with a Parent Who Has Cancer by Lynnette Wilhardt

Created by teens, this book is a collection of verses and images that depict how it feels living with a parent who has cancer.

KEEP CALM AND TALK WITH SOMEONE WHO LOVES YOU

Angel Foundation helps Twin Cities parents, caregivers and children live happier lives by relieving the financial and emotional stress caused when cancer strikes.

All programs are provided free of charge.

angel foundation

1155 Centre Pointe Drive, Suite 7 Mendota Heights, MN 55120
Phone: 612-627-9000 Fax: 612-338-3018

mnangel.org