KEEP CALM AND TALK TO SOMEONE THAT LOVES YOU

Angel Foundation provides additional support programs in the Twin Cities for parents, caregivers, young adults, teens, preteens and children.

All events and programs are free.

Help when cancer strikes
angel foundation

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FACING CANCER *together*

A SUPPORT GUIDEBOOK FOR TEENS

When Your Parent Has Cancer

Help when cancer strikes
angel foundation

THIS BOOK IS FOR YOU.

If your parent or grandparent has been diagnosed with cancer, this guidebook is for you.

This resource is to help you explore and learn more about what it means to be a teenager with a parent or grandparent with cancer. You are probably experiencing a wide range of thoughts and feelings like anger, sadness, fear, and worry. These are all very real and normal feelings. *You are not alone.*

This book will explore:

- Cancer basics
- Thoughts and feelings
- Coping and support ideas

Feel free to use this book as you wish. Doodle, write notes, or share with your friends. Sometimes friends are the best medicine to help you work through what is happening when a parent or grandparent is sick.

Find a digital PDF copy of the guidebook on our website: www.mnangel.org

You've Just Learned Your Parent or Caregiver Has Cancer

Do you feel in shock? Are you numb? Confused? Angry?

What do *you* know about cancer? Cancer is a scary word, isn't it? What does having cancer mean to you? It is important for you to decide how much or little information you need or want right now. You may want to reread this guidebook later when you feel ready.

Here is some basic information to understand *right* away before you continue reading. Consider the **bold words** as you read.

Facts:

Almost everyone knows someone who got very sick or died from cancer. According to the Center for Disease Control, nearly 14 million Americans with a previous cancer diagnosis are living in the United States. People are **living longer** after a cancer diagnosis because of advances in early detection and treatment. People also have a better quality of life during cancer treatment due to a significant increase in research in the last 10 years.

You Did Not Cause This Diagnosis:

This seems like an obvious statement, but it is often helpful to hear. There is nothing you said or did that caused your parent or grandparent's illness. Cancer is caused by a variety of factors; most of which doctors still do not fully understand. The most *important thing* to know is that **you are not to blame**.

You Are Not Alone:

There are other teens experiencing very similar feelings that you are right now. Many feel alone and helpless. You may feel hesitant to talk with your parent or grandparent because you want to protect them from your feelings. If you aren't yet ready to ask questions, find a friend, school nurse, or a trusted adult to talk to. This may begin to ease the feeling of being alone and eventually make it easier to talk to your parent or grandparent. **You are not alone.**

What is Cancer?

Cancer is a group of many related diseases that all have to do with **cells**. Cancer happens when cells that are not normal grow and spread very fast and do not know when to stop. When a clump of abnormal cells group together, they form **tumors** that can then take over and destroy surrounding cells. This cell damage can cause the body to become very sick.

Common types of tumors:

- **Benign:** Tumors that are not cancerous and can be easily removed from the body.
- **Malignant:** Tumors that consist of abnormal cells that are out of control and have divided too many times. This type of tumor is cancerous. When a cell has broken free of the primary tumor, the cancer has spread and is called **metastasis.**

What kind of cancer does your parent or caregiver have?

The cancer will typically be named after the body part the cells or tumor is affecting (e.g. breast cancer, colon cancer, brain cancer, etc.). One type of cancer that does not form a tumor is **Leukemia**, which is a blood cancer that is found in the **bone marrow**. **Lymphoma** is another type of cancer that starts in the cells that are part of the body's **immune system** (e.g. lymph nodes, spleen, etc.).

Use this space to write down your parent or caregiver's type of cancer and treatment plan:

What Does Treatment Look Like?

Typically everyone's treatment is different. It can include surgery, chemotherapy, radiation, or all of the above.

- **Surgery** – This is the removal of a tumor. A surgeon will operate to remove the tumor and surrounding cells from inside the body. Your parent or grandparent 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 is given at intervals to help your parent or grandparent recover after they receive it each time.
- **Radiation** – This is radiotherapy that uses high-energy rays that shrink and/or destroy cancer cells. It may be given *outside* the body through a machine or radioactive material placed *inside* the 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 treatment or when blood draws are needed. It is generally easier and less painful than an IV or finger pokes. Numbing cream can often be used. Ask to see what your parent or grandparent's port looks like.
- **Bone Marrow Transplant (BMT)** – This is a procedure where cells are harvested from either a donor or the patient's own bone marrow. These BMT cells are used to help replace diseased cells with non-cancerous cells.

Treatment Side-Effects:

There is no getting around it: side-effects from treatment stink! Your parent or grandparent may have all of the side-effects listed below, or just a few. It is helpful to become familiar with them and prepare you for what is ahead.

Common treatment side-effects:

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

Your parent or grandparent has an important group of medical professionals to help them, and they each play an important role. You can ask questions to learn how they are helping!

My Parent or Grandparent's Care Team:

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

Here is a space to write down questions:

Consider Visiting During Treatment

You may be curious about visiting the hospital or clinic and seeing how treatment works. Visiting will also give you a chance to take your list of questions to ask a care provider. Remember, **your mind is very powerful.** If you see what chemo or radiation actually looks like, it may help you cope better with the unknown. This will also give you an opportunity to spend one-on-one time with your parent or grandparent and ask them specific questions. You may be worried beforehand, but those feelings are all very normal and okay to have!

Ideas to help comfort you and your parent or grandparent during treatment:

- Adult coloring sheets and coloring pencils – coloring can be relaxing and help pass the time.
- Blankets and pillows – tuck your parent or grandparent in.
- Books or magazines – read a book aloud or share a magazine.
- Meditation or relaxing music – find something soothing to listen to.
- Sleeping mask – your parent or grandparent may want to rest.
- A journal – you can write back and forth in it together.
- Crossword, Sudoku, or other mind games.
- Movies – watch a favorite movie together.
- Knitting or crocheting needles and yarn – learn a new craft together.
- Snacks and fluids – keeping hydrated is important.
- Warm socks and knit hats – clinics and hospitals can be cold.
- Lip balm – sometimes this helps prevent mouth sores.
- Unscented lotions – hand massages are very relaxing and it can also make you feel helpful.
- Provide a cold wash cloth.

Recovering From Cancer

You may begin to hear words like **prognosis** and **remission** as time goes on. A **prognosis** is the estimate of how well someone's body is responding to treatment. The purpose of treatment is always **remission**, which means there are no signs of cancer in the body. Unfortunately, this can often be a long and winding road. It can wear the entire family down and feel like a roller-coaster of emotions. During that time, there might be a **relapse** or **recurrence**, which means the cancer has returned.

Relapse or **recurrence** often may mean more treatment is needed. Talk with your parent or grandparent about the new treatment plan. Remember to be open and honest with your feelings. You may feel like you need to ask your parent or grandparent **if they will die**. This is a very normal question to ask when someone is sick. You might hear responses like this:

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

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 the same as 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?** Do you think your parents will tell you everything? If you have siblings, do you think your brothers and sisters might take it hard?

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 (school, friends, life) and adding the stress of your parent or grandparent's illness can sometimes feel like too much to handle.

Your parent or grandparent may ask for some additional help around the house. They may ask you to do extra chores or babysit your siblings more often. These routine changes can be hard, because you may feel **guilty** or **resentful** for wanting to spend time with your friends or participate in afterschool activities. However, you may find that having your parents trust you with additional responsibility will help bring you (and the family) even closer together.

Think about ways you can help around the house, or how you can help your parent, grandparent, or other adults in your family. A little help goes a long way and you may feel more included when helping to ease the burdens for your family.

You may see **physical changes** to your parent or grandparent. Cancer treatment is rough no matter what type it is. Chemotherapy is a treatment that is designed to destroy abnormal cells, but it also can damage healthy hair cells, which can mean thinning hair or hair loss. Your parent or grandparent's **self-esteem** may be affected and this can sometimes be hard to watch. This may feel **embarrassing** for both of you. Perhaps you can offer to go shopping for hats or scarves with them, or talk about how they are feeling about these changes.

Use this space to write down what has changed in *your* life:

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What About Your Parent or Grandparent?

Your parent or grandparent will have their own ups and downs, too. Their moodiness or irritability might increase as they worry about how to handle treatment and care for their family.

They might be feeling:

- Lonely
- Angry
- Upset
- Sad
- Afraid
- Frustrated

These feelings may be very similar to what you are feeling. It Is common for the parent or grandparent to try and protect their children. The same might go for the child wanting to hide their feelings and protect the adult. 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.

What About Me?

What about *your* feelings? What about the changes that are affecting *you*? Taking care of your emotional needs will be a very important part of your job during this time.

Use this space to write what you are thinking and feeling:

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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
- 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

- Play a favorite sport
- Go for a walk
- Do yoga

Relax

- Learn breathing techniques
  - Practicing new 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

Use this space to write down **self-care** ideas for yourself:

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Journaling Topics

Don't be worried about what you write.

Just Write!

- What inspires you?
- Write about a time when you tried something new.
- I just want to scream! Write about what is frustrating you right now.
- Write about a time when you made a sacrifice for someone else.
- If you could take a dream vacation, where would you go?

Who is your Support System?

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

Who can you ask for help?

- Personal friends and peers
- Grandparents, aunts and uncles
- School teachers, nurses, or counselors
- Spiritual leaders
- Family friends

SUPPORT

Get Help
When You Are Feeling Down

You might still be feeling **helpless** and **hopeless** during your parent or grandparent's treatment. If these feelings are interfering with your school work, friends, or family life, you may need additional support. Don't worry: these feelings are **very normal** and there are many local support groups or counselors to help you through the tough times.

Resources that can help:

- Angel Foundation programs
- Social Worker
- School teacher or counselor
- Spiritual leader
- Oncology Therapist

Use this space to list any worries and concerns that are interfering with your life.

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Growing Stronger As a Family

Remember, you can revisit this guidebook again when you think about all the information you've been given. It is a lot to digest at one time and it's okay to put a book like this aside for a while. Come back to the parts you may need at various times in the future. It's important to use what you've learned to move forward together as a family and discover your strengths together.

Count Your Blessings

In what ways are you fortunate?

Make a list of 10 things you are grateful for, including people and things, events and experiences — both past and present. Each day, for the rest of the week, add 10 more items to your list. At the end of the week, you will have written down **70 reasons** to be thankful!

Additional Local and National Resources:

Angel Foundation
www.mnangel.org

Gilda's Club Twin Cities
www.gildasclubtwincities.org

KidsHealth
www.kidshealth.org

Kids Konnected
www.kidskonnected.org

American Cancer Society
www.cancer.org

Books:

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.