

Supporting children and young adults with a terminally ill parent.

NAVIGATING GRIEF & LOSS: PATHWAYS TO HEALING

Cancer Loss Guide for Adolescence (13-18 years)

Prepared for Elizabeth's Smile

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For those who are navigating life after cancer loss – we are holding you in our hearts and thinking of you.



Written by experts in children's grief and development, Dakota Becker, MSW, LMSW, our Clinical Grief Consultant, and Emma Swift Lee, M.Ed., our Child and Family Development Consultant, this guide helps you navigate the death of a parent to cancer.

At Elizabeth's Smile, we believe that when children experience the death of someone close to them, that does not have to mean they have to lose their childhoods. If you're reading this, that means a child you care for is grieving the loss of someone important to them, and we can imagine you're likely grieving this loss, too. We are so glad you're here and are also so sorry for the pain you're carrying.

While children have many deeply meaningful relationships in their lives, this specific guide is written for adults who have assumed primary caretaking responsibility for a child who has lost a parent to cancer.

Please know that we're working on writing more guides just like this one to support siblings, extended family members, teachers, and more.

We know you're here because you deeply care for the children in your life; in fact, you care so much that you've sought out resources and support while you both grieve a painful loss. It might be hard to believe, and we want you to know that while you can't protect your child from their grief or change what happened, you are a gift to her during this time and can be for the rest of your life.

We recognize how unique each individual and family's experience of cancer and grief is, and for the purposes of this guide, we will be using the term 'cancer loss' broadly and focusing on experiences after a loved one has died. We will also be writing under the assumption that your child was aware their caregiver had cancer. We know that all families are different and communicate in different ways, so please keep in touch as we work on resources for children who did not know about their caregiver's illness, in addition to more resources on anticipatory grief, specific types of cancer-related loss, and supporting caregivers and children before their loved one dies.

If this feels hard, that is because it is hard. No one prepared you for this, and while there is no handbook on how to grieve while also caring for grieving children, we hope the information, suggestions, and ideas in this guide can offer some understanding, relief, and confidence as you and your children continue navigating life after loss.

Remember – there is no such thing as "perfect parenting," and there is no "right" way to have these hard conversations. So, if you take anything away from this introduction, please know that you already have within you what your children need – your love, care, presence, and curiosity.



Welcome to our guide for adolescence. Written by experts in children's grief and development, Dakota Becker, MSW, LMSW, our Clinical Grief Consultant, and Emma Swift Lee, M.Ed., our Child and Family Development Consultant, here you will find useful information about how children at this age understand and respond to death, learn how to support children at this age and how to talk to them about cancer.

As children grow and develop, their grief will grow and change with them. We encourage you to continue answering your child's questions honestly and check in on their understanding. This could sound like:

- "Tell me what you heard me say"
- "Tell me what you think that means"
- "It is okay to feel confused...am I making sense, or should I repeat myself?"

How children understand death

How children might respond to death

At this age, children have an adult-level understanding of death + also have the cognitive skills to understand abstract concepts such as spirituality, life after death, and meaning-making.

Teens may have strong beliefs about fairness, suffering, and what happens after death. They may be questioning the beliefs others share and may have ideas about what does and doesn't help them when they are grieving. They also may have a good sense of when people are being honest with them or when parts of the truth are being hidden or "sugarcoated" for their benefit.

As children move further into adolescence, they will continue to naturally seek connection and conformity with peers. Children at this age will avoid "being different" and may act like "nothing is wrong" for fear of standing out. Children may also feel insecure, embarrassed, or shame.

Children may continue to experience anxiety, sadness, anger, irritability, and physical pain (i.e., headache and stomach ache).

Feelings of distrust/fears of being abandoned could arise as children navigate many "firsts," such as their first relationship, first dance, entering high school, graduating high school, etc.

Children may also exhibit aggressive or callous behaviors as their best attempts at combating feelings of helplessness and exerting control.

Suggestions for supporting children at this age

- Some teenagers may not ask questions, but that doesn't mean they
 aren't wondering about cancer and loss. It can also be very helpful to
 ask teenagers what they think. They may understand more than you
 realized, or they may surprise you with an explanation that isn't quite
 right or that is different from what you think. This can be an opportunity
 to explore ideas, information, and beliefs they may have.
- Offer accurate information to your child when they express curiosity or confusion about their parent's death. It will be important for you to consider how involved they were in their parent's illness journey and acknowledge what that experience may have been like for them.
- Teens may have had to grow up faster than their peers, so it will be important for the adults around them to give them permission to do "teen things" and avoid putting adult responsibilities onto them.
- Without pressuring teens to talk, create space and/or opportunities for connection, whether that be related to their thoughts/feelings around the death of their parent or the other parts of their life they may want to share with you.

Gently remind your teen:

- "You will always be loved"
- "You will always be taken care of"
- "Your [parent] loved you so much and did not want to leave you"
- "It is okay to feel angry with them, with the world, and even with me. Your anger makes sense."
- "We can find ways to remember [parent] and still feel connected to them"

Model and explain expressions of grief. This will help your child understand that everything they're feeling is normal. So normal, in fact, that there is this little word called grief to describe the feelings they're having.



Remind and reassure children frequently that nothing they said or did caused their person to die. They are not to blame.

Maintain close communication with your child's school (i.e., teachers, school counselor) to understand what adults in a different environment are noticing regarding your child's academic functioning, social/peer relationships, general mood/demeanor, and capacity to sustain attention.

Talking to kids at this age about cancer

These are some of the most important ideas about cancer and loss to communicate to children this age:

What is cancer?

- Mom was sick with cancer. What do you know about cancer?
- Cancer is a very serious illness that happens when some cells in people's bodies grow out of control. These cells are called cancer cells. They grow much faster than they are supposed to and sometimes form solid lumps of cancer cells called tumors.
 Sometimes, the cancer cells spread throughout the body and form tumors in many places.
- Our bodies are naturally good at fighting off cancer cells, but sometimes, the cancer cells find ways to avoid our body's natural defenses. That's when people get sick with cancer.
- Cancer cells and tumors can make people very, very sick and can even sometimes make them die. Cancer can cause pain and can hurt the body's ability to work the way it is supposed to.
- There are many different types of cancer, and some are more serious or hard to get rid of than others. What do you know about the cancer Mom had?

• Why did they have cancer?

- Most of the time, no one knows why someone gets cancer.
- There are some cancers that scientists have found are caused by certain things in our environment, like smoking cigarettes or too much exposure to UV rays in the sun or tanning beds. Often, cancer happens without anyone knowing why.
- It can be hard to not know why someone gets very sick. What do you think?

· Emphasizing that no one is to blame or at fault

- It's not anyone's fault that Mom had cancer. There's nothing Mom, you, or anyone else did to make it happen.
- It's okay if you feel upset that Mom got cancer. You may even feel angry at her for getting sick or dying. Sometimes I feel angry too. I know that she wanted to be here with you more than anything.

What was done about the cancer?

 People get treatment from cancer doctors called oncologists to try to get rid of cancer.

Surgery

- Mom had surgery to take out as much of the cancer as possible.
 What do you know about surgery?
- Mom was sore after she had surgery, but she was asleep during surgery, so she didn't feel any pain. What questions do you have about the surgery Mom had?
- The surgery helped Mom by helping her live longer with her cancer/making her pain better, but it was not able to kill all of the cancer cells.
- The doctors couldn't do surgery to get rid of Mom's cancer because the cancer had spread to a lot of places in her body.
 Surgery just would have made her feel more sick and would have put her at risk of getting other infections.

Chemotherapy

- The doctors gave Mom very strong medicines called chemotherapy. What do you know about chemotherapy?
- Because her chemotherapy was so strong, it also sometimes made her feel tired or sick. It helped Mom by helping her live longer with her cancer/making her pain better, but it was not able to kill all of the cancer cells.

Radiation

- Mom got some special treatments called radiation therapy. What do you know about radiation?
- Radiation uses machines that create certain types of energy waves to try to help fight the cancer. It helped Mom by helping her live longer with her cancer/making her pain better, but it was not able to kill all of the cancer cells.
- Sometimes, chemotherapy/radiation is very, very strong and can also make people feel sick.
- Medicines like chemotherapy/treatments like radiation fight cancer by killing very fast-growing cells like cancer cells. Sometimes, they also kill other healthy, fast-growing cells like the cells in our hair follicles, stomach lining, and bone marrow, where our bodies make blood and white blood cells that fight infections. That's why people who take cancer medicine often lose their hair, feel sick, or get really sick from infections like the flu.
- Did you see Mom feel sick from cancer or cancer treatment? What did you notice?

• Why didn't the treatment work?

- Even though it didn't stop the cancer, it doesn't mean it was the wrong treatment.
- Mom and her doctors did everything they could to help her get better. Sometimes, the cancer is stronger than even the strongest chemotherapy or other treatments.
- Lots of researchers are making better cancer treatments and learning more about how to prevent cancer every day. Hopefully, someday soon, there will be treatments that are stronger than any kind of cancer.

• How did they die?

- Cancer cells can make people very, very sick by hurting their body's ability to do things like breathe, eat, or fight off other sicknesses like COVID or the flu. Sometimes, even the best medicine we have isn't strong enough to fix this.
- Doctors and nurses give people medicine to help them feel better even when they're very, very sick from cancer. They gave Mom medicine that helped her not have pain. They also gave her medicine that helped her feel calm.
- Sometimes, people's bodies become too sick from cancer for them
 to be able to handle any more cancer treatment since cancer
 treatment is so strong and can be so hard on the body. Once Mom
 got really sick, if she had gotten any more cancer treatment, she
 could have died even faster from the treatment.

Cancer that runs in families

- Some types of cancers are more common in some families. These types of cancers are caused by certain genes, which can be passed down in families. These types of cancer are called hereditary cancers. What have you heard about these kinds of cancers?
- Mom's cancer was not hereditary. Just because she had it does not mean you or anyone else will have it.
- Mom's cancer was hereditary, and other people older than her in her family had the same type of cancer. That doesn't mean anyone else in our family will definitely get sick with cancer. You may not have the same cancer gene that mom had. There are a lot of things we can all do to help keep ourselves and our bodies healthy, like going to the doctor for checkups every year and getting special tests to learn if we each have that cancer gene.
- I don't have cancer and you don't have cancer. Our bodies are healthy.
- People typically don't get this kind of cancer until they're much older than you are. We can talk to a doctor about when is a good time to get any special testing.

Addressing other hard questions

It's okay to not always have the answer. You can try saying:

- That's a really good question. I don't know the answer to that.
- I wonder about that, too. Sometimes, it helps me to think about (share your beliefs or things that bring you comfort).
- What do you think?
- What helps you when you feel upset or worried about that?
- We can't always know what will happen, but what I do know is that you will always be loved, and we can get through this together.

Have questions about other grief topics?

Our experts have written a series of guides that help people understand some of the core issues that are present when one grieves.

Please follow the links to learn more about these topics, ranging from grieving before a loss (anticipatory grief) to explaining to a young child that someone has died, preparing for funerals, understanding how to help, and how children understand death at different developmental ages.

Resources for supporting yourself

Widowed Parent → <u>www.widowedparent.org</u>

Videos and written resources for understanding grief and supporting yourself and your child through grief. Includes additional recommendations for books, support groups, children's grief camps, and more.

GriefShare → www.Griefshare.org

Find in-person grief support groups near you, or join online groups.

Open to Hope → <u>www.opentohope.com</u>

Articles, books, podcasts, and videos of professionals and other bereaved people sharing their experiences with grief.

Lotsa Helping Hands → <u>www.lotsahelpinghands.com</u>

One option for easily coordinating and mobilizing your support network after a loss to help with tasks like meals, child transportation, and chores.

- https://www.empathy.com/
 - *similar organization that supports with the logistics of grief*

Life of Dad → www.lifeofdad.com

Research shows that men tend to have fewer built-in support networks to navigate parenting and grief. This site has blog posts, videos, podcasts, and Facebook groups specifically to help support fathers.

https://refugeingrief.com/ https://whatsyourgrief.com/

Additional resources for cancerrelated information

American Cancer Society

This site has a number of guides on explaining cancer to children, helping them understand death, and ways to provide support after the death of a loved one.

- https://www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer/dealing-with-parents-terminal-illness/how-to-explain-to-child.html
- https://www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer/dealing-with-parents-terminal-illness/how-kids-cope-by-age.html
- https://www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer/dealing-with-parents-terminal-illness/kids-understanding-death.html

Cancer.Net from the American Society of Clinical Oncology (www.cancer.net)

Trusted information about all types of cancer and cancer treatment. This site provides additional information as you talk with older children and teenagers who may have more questions.

Resources for supporting kids & teens

Dougy Center: The National Center for Grieving Children and Families (www.dougy.org)

Expert information and resources for children of different ages and for their caregivers to help children understand and navigate grief. Explore activities for kids of each age group.

National Alliance for Children's Grief (www.nacg.org)

Comprehensive resources for understanding children's grief, talking with children about grief, and finding local and online support.

- https://indd.adobe.com/view/246ac201-44b2-4dd2-b7cbb53c2094b64b
- https://indd.adobe.com/view/e66b0d18-90f8-4edc-a046e1cd1b3bd859

Sesame Street Workshop

Storybooks, information guides, activities, and videos to help children learn how to cope with grief.

• www.sesameworkshop.org/topics/grief/

Camp Kesem

Week-long camps held around the country for kids affected by a parent's cancer.

www.kesem.org

Empower

Mentoring programs pairing grieving children with adults who lost a parent as a child, in order to empower and support them on their grief journey.

https://weareempower.org/

Kids books about grief

While grief often occurs in different forms before someone dies, these books are intended to support children and their families after a loss has already occurred.

Something Very Sad Happened: A Toddler's Guide to Understanding Death

A Kids Book About Death by Taryn Schuelke

Why Do I Feel So Sad?: A Grief Book for Children

What Does Grief Feel Like?: Leigh, Korie, Malbrough, Mike: 9781631987069: Amazon.com: Books

When Someone Dies: A Children's Mindful How-To Guide on Grief and Loss

One Wave at a Time: A Story about Grief and Healing

I Miss You: Grief and Mental Health Books for Kids (A First Look at...Series)





Finding Grief Support for Kids & Teens Near You

https://elunanetwork.org/

https://nacg.org/find-support/

https://www.dougy.org/program-finder

Citations

https://cancercare.org/publications/66helping_teenagers_who_have_lost_a_parent

https://cancercare.org/publications/52helping_children_who_have_lost_a_loved_one

https://judishouse.org/wpcontent/uploads/2023/02/Commongriefreactions-2023.pdf

https://judishouse.org/resources/common-grief-reactions/

https://judishouse.org/wp-content/uploads/2023/10/Developmental-Differences-in-Understanding-and-Reacting-to-Death-1.pdf

https://www.dana-farber.org/patient-family/support-services/family-connections/for-patients/talking-children-about-cancer

https://www.zerotothree.org/resource/helping-toddlers-cope-with-grief-and-death/

https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Children-And-Grief-OO8.aspx

https://childmind.org/guide/helping-children-cope-with-grief/

https://www.annafreud.org/resources/under-fives-wellbeing/common-difficulties/bereavement/