

Supporting children and young adults with a terminally ill parent.

NAVIGATING GRIEF & LOSS: PATHWAYS TO HEALING

Cancer Loss Guide for Preschool-Age Children (3-5 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 preschool-age children. 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 might respond to death

At this age, children have a concrete and limited understanding of death.

They may ask many questions about if the person will be coming back to life, if they can see the person again, if their body is in pain, or if they're hungry or cold.

Based on their cognitive development, children at this age believe in magical thinking (i.e., that their wishes can come true). Keep in mind that may mean your child believes if they wish for their parent to come back, that could actually happen, and also if your child had any angry or mean thoughts towards their parent before they died, your child might believe their parent's death was a punishment or their fault.

It is common at this age for children to regress to younger behaviors both behaviorally and emotionally. Preschoolers might temporarily lose skills they've previously mastered, such as tying their shoes, sleeping independently, using the potty, dressing themselves, etc.

Children often show an increase in tantrums or clingy behavior, particularly at moments of separation (i.e., school drop-off and bedtime). You might also notice your child complaining more about pains/aches in their body, such as stomachaches.

Your child might show changes in their eating and sleeping patterns in addition to potentially experiencing nightmares.

Your child might push away caregivers and struggle with self-soothing and being comforted.

Your child is likely to ask frequent and repetitive questions about death and express worries about their own health/safety and the health/safety of other people they love.



Suggestions for supporting children at this age

Start with a short, simple explanation of what happened in a language young children can understand, and then let their questions guide what else to share. Use concrete, clear, and simple language to explain death (i.e., using words such as died, body stopped working, cannot come back)

- We encourage you to avoid using terms that might be confusing for a
 young child (i.e., saying things such as "sleeping" "went away" or
 "resting"). Unfortunately, using words like this often inadvertently
 increases a child's distress or leads to fears of sleep/separation.
- For families who hold and practice religious, faith, and spiritual beliefs –
 we encourage you to always honor and respect your traditions while
 also meeting your children where they are developmentally. Young
 children do not yet understand the concept of heaven/afterlife or
 anywhere that is not in their immediate surroundings. Unfortunately, the
 idea that a parent "went to heaven" often causes children more distress
 instead of providing them with relief because it can make a child
 wonder when their parent will be coming back in addition to believing
 that their parent chose to leave them.

Gently remind your child (as they will likely ask the same questions repeatedly):

- "It is so sad Daddy died...Daddy loved you so much and did not want to die."
- "I know you want Mommy to come back...I want Mommy to come back, too. But remember, when mommy died and her body stopped working, that means she won't be coming back. We can always love Mommy and find ways to remember her."
- "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"
- "We can find ways to remember [parent] and still feel connected to them"
- "You really wish [parent] was still alive. I do, too. I know that [parent] wished she could have stayed alive to be here with you, too."

Create safety through routine → helping a child understand who will care for their day-to-day tasks (i.e., who will pick them up from school/daycare, cook their meals, put them to sleep)

- Give young children developmentally appropriate choices
 - o "Do you want to wear the blue shirt or the red shirt?"
 - "Do you want waffles or yogurt for breakfast?"

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 big 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.

Children at this age are much more likely to express themselves through play rather than talking.

Provide them with opportunities to express their grief through play, physical outlets, or art.

- Can stomp like an angry elephant or roar like a lion
- Angry scribble with crayons
- Rip up tissue paper
- Give themselves butterfly or bear hugs for comfort
- Draw their grief feelings
- Write a card or draw a picture for their loved one who died
- Plant flowers outside to remember their person who died



Talking to kids at this age about cancer

Given that kids at this age have a limited understanding of death, it can be helpful for them to understand that their parent died of a sickness called cancer. Being too vague, unfortunately, can create more anxiety and distress for young children.

This could sound like:

- "Mom was very, very sick with something called cancer. This is a very
 different type of sickness than getting a cough or having a tummy ache.
 Mom isn't here anymore because she died from cancer, which means
 that her body stopped working and she won't be coming back, but we
 can still think and talk about her. She loved you very much, and you will
 always be loved."
- "Mommy died. This means her body stopped working, and the doctors weren't able to fix it."

Children at this age are likely to ask the same questions repeatedly, which is their way of trying to understand and make sense of their experiences. Common themes of repetitive questions have to do with the person coming back, whether they will see the person again, etc.

Some example responses could be:

 "Sweetie, remember when I told you that Mommy died and her body stopped working? That means we won't see her at XX, but if you want, we can look at pictures of her when we get home."

It is often painful to have to repeat this, so please take care of yourself during these moments and remember that by answering your child's questions, you're helping them ease their own anxiety.

The truth often provides children with comfort.



Be prepared for questions about what happened to their body and where the person's body is now.

Given how children at this age are concrete thinkers, they often are curious about what happens to the body after someone dies.

Give yourself permission for your answers to be simple and concrete... which could sound like:

- "When a person dies, their body stops working, which means their heart stops beating, their lungs stop breathing, and they can't eat, laugh, talk, cry, or poop anymore."
- "When someone dies, and their body stops working, their body doesn't
 have any feeling in it anymore (i.e., they can't feel hot or cold), and so
 that person's family needs to decide what to do with their person's
 body. Every family is different, and in our family, [person's body] got
 taken to a place called a funeral home, where they're taking care of her
 body for us."
 - o If the person is to be cremated, you might say, "Since Daddy died, his body doesn't feel anything anymore; so we're going to have Daddy's body cremated, which means it will go in a special room that gets very, very hot. The heat will turn his body into ashes. We can keep some of them to remember him, or we can put some of them in places he loved, like mountains or the beach."
 - If the person is to be buried, you can (as the child asks and expresses interest in knowing) say, "One way we will take care of Mommy's body and remember her is by having her body in a kind of box called a casket. We're going to pick a special place to bury her body, and then we can go visit where they put her body."

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