



Supporting children and young adults with a terminally ill parent.

NAVIGATING GRIEF & LOSS: PATHWAYS TO HEALING

Cancer Loss Guide for Infants (0-12 months) & Toddlers (1-3 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.



With Care.

The Elizabeth's Smile Team



Welcome to our guide for infants and toddlers. 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
<p data-bbox="68 869 779 1087">At this age, children do not have the cognitive skills to understand the concept of permanency; thus, they do not yet understand death as something permanent and irreversible.</p> <p data-bbox="68 1146 756 1360">Rather, infants and toddlers experience death as separation → they notice and know that their loved one is gone and their world is different, but they expect this person to return.</p>	<p data-bbox="837 777 1542 1129">This age group will likely express their grief through observable behaviors related to bodily functions (i.e., sleeping, eating, bathing, toileting). It is common for children who have lost a parent at this age to push away from caregivers, have trouble settling/soothing, or refuse to be held/be fed/ be bathed by another adult.</p> <p data-bbox="837 1188 1549 1453">It is also common to see children at this age appear unaffected, however, they may search for the person who died or ask about their return. You may notice increased tantrums, a heightened need for closeness and increased distress upon separation.</p>

Suggestions for supporting children at this age

Use concrete, clear, and simple language to explain death (i.e., using words such as died, body stopped working, and 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 and separation.
- For families who observe religious and spiritual beliefs around death – we encourage you to always honor and respect your traditions while also meeting your children where they are developmentally. Young children may 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” could cause 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, and put them to sleep)

Talking to infants and toddlers about cancer

The decision to tell children at this age that their parent died of cancer is up to each family. Given that infants and toddlers do not yet understand the concept of death or illness, we often recommend that caregivers follow their child’s lead by offering the information that children express direct curiosity about. For example, it would be important for a child to know that their parent died, and it is not necessary to share how their parent died unless the child explicitly asks.

“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.”

Toddlers do not need complex descriptions of cancer. However, using simple, consistent language can help them as they start to understand concepts like death and illness.

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](#).



Citations

https://cancerca.org/publications/66-helping_teenagers_who_have_lost_a_parent

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

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