

Supporting children and young adults with a terminally ill parent.

NAVIGATING GRIEF & LOSS: PATHWAYS TO HEALING

Cancer Loss Edition

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

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Understanding the rationale behind how this guide is organized

Children grieve and cope with death very differently than adults do – in large part due to their age and developmental stage. Developmental stages refer to the developmental tasks and conflicts all children navigate and work through.

Given the importance of child development in understanding a grieving child's experience, any invitation, recommendation, or suggestion in this guide will be both grief-sensitive and developmentally-informed. Just like there is no right way to grieve, there is no right way for a child to navigate their development. If possible, try to remind yourself that your child's behavior is communication – and it is okay if their age in years/months does not line up with the developmental categories we've outlined below.

If you have any concerns or questions about your child's development and/or mental health, we always encourage families to speak with their child's pediatrician as a first line of support. At the end of this guide, we provide information and resources on when to consider seeking mental health support for your child after the death of a loved one.

At Elizabeth's Smile, we recognize and celebrate our differences, so if some of the information below does not apply to your family or feels redundant, please feel free to take what you need and leave the rest.

Reflecting on and answering hard questions

Families communicate in many different ways, so we invite you to reflect on some of the below questions:

- What conversations, if any, have happened with your child regarding their parent's cancer?
 - Were they aware their parent was sick?

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- Were they aware their parent was dying/going to die?
- Were they involved in their parent's dying process?
- What conversations, if any, have happened with your child regarding their parent's death?
 - How is death talked about/not talked about in your family?
- Was their parent's death something they had advance notice of? Or was their parent's death sudden?
- How involved was the child's parent who died in the child's daily routines (i.e., feeding, sleeping, bathing, toileting, getting ready for school, etc.)?

Remember, there are no right or wrong answers to these questions. It is also perfectly normal and okay if you don't know the answers or if you came to this guide seeking answers. We prompt your reflections on those questions because when talking with your child about their parent's death, it will be important for you to consider where your child is starting from.

Talking to children (generally) about cancer-related death

Talking to a child about death or dying is often challenging, confusing, and difficult. The suggested ideas and phrases below can provide a starting point as you navigate these conversations. Every circumstance is different, and there is no one right way to talk about cancer or loss. You can use whatever words and details are right for your situation and your family.

Some invitations on places to start:

1. Follow your child's lead, assess what the child already knows, and consider how aware/ involved your child was in their caregiver's cancer journey

- "You know how Daddy was sick with cancer...remind me what you think that means"
- "Mommy's cancer made her body so sick that she died and her body stopped working"

2. Use concrete language (particularly for younger children) when explaining complex topics

- Using words like "died," "death," "body stopped working"
- Avoiding euphemisms or softer words like "went to sleep," "went away,"
 "gone"
- 3. Be mindful of the setting when talking to children about hard topics
 - If possible, can someone close to the child share the news in an environment the child feels comfortable in

 If possible, can the news be shared when the child will have time to process afterward and be near caring adults (i.e., not before school or before bedtime)

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- If you have children of multiple ages, consider if it would feel best for you to share the news with them individually or together
 - Since they may need different things based on their developmental understanding of what's happening
- 4. Model for your children **being okay with 'not knowing'** answers to their questions
 - "I'm so glad you asked that question. It is so important. I don't know the answer right now, but I'll find out for both of us."
 - If it's an older child, you can add, "maybe we can look into the answer together"

5. Express your own emotions to your children while also reminding them that they are not responsible for your feelings and will still be loved/taken care of

 "This is all new to me, too. You might see me cry and that's okay because that's my body's normal way of showing my sadness. You might also see me feel worried or angry, and I want you to know that even when I have big feelings, I will still be here to take care of you. We will get through this together."

By using yourself as a model for your kids, you give them permission to have and share their own emotional experiences with you.

6. Remind your children:

- Nothing your child said or did (i.e., none of their thoughts or actions) caused their loved one to get cancer or to die
- Their loved one did not choose to have cancer or choose to die...cancer is not a choice
- You and your child cannot "catch" cancer from a sneeze, tummy ache, headache, etc. ...cancer is not contagious
- Who will care for them on a day-to-day basis
- They are loved, cared for, and safe

Supporting your child and yourself after a cancer-related death:

1. Lean into community and networks of support

- With your child's awareness, share the news of their parent's death with their pediatrician, school counselor, and teacher(s)
- Depending on your child's age, it may be important for your child to share their input on how much they want their teacher(s) to know. You and your child can think together with their school counselor and/or teacher(s) on a grief support plan for when they go back to school
- Talk with your assigned hospital social worker to understand what grief support groups are available for adults

2. Be curious about different ways of grieving

- Given that grief is highly individual, it looks and feels different for everyone. While families can experience the same loss, their grief is often incredibly different. Remember – there is no right or wrong way to grieve.
- Some children and teens might cry, others might seem unaffected and want to be left alone, some might dip in and out of their grief, going from crying/tantruming to playing, others might appear fidgety or have trouble sitting still, while some might not want to be alone at all and cling to those around them.

3. Be with your child's grief

- In grief, people are quick to offer advice, give their unsolicited opinions, or try to fix it. Listening and 'being with' your child's thoughts and feelings, instead of judging them or trying to rush your child through their experiences, is a gift to them.
- You'll likely need to adapt your support to meet your unique child. If your child pushes back against your support or says they're "fine," we encourage you to respect their boundaries and also continue offering your support. Sometimes, children need to talk or play, and sometimes, it can be incredibly healing to have a caring adult sit or play with them without the pressure of talking. You'll figure out what feels best for you and your child.

P.S. You deserve to have someone (whether that is a friend, family member, or professional sit with you in your grief as well)

4. Create safety and predictability through routine

- So much about a child's life is out of their control. When a child loses a
 parent, it is the ultimate loss of control and can make their world feel
 unsafe and unpredictable. One of the best ways to create safety for
 children and teens is to provide routine and consistency while also
 leaving space for flexibility.
- Some examples might include sticking with wake-up and bedtime routines, scheduling regular playtime, or extracurricular activities. Other ideas include a scheduled or one-on-one daily check-in.

5. Collaborate with your child on family values and responsibilities

- Family dynamics and roles/responsibilities often shift after a loved one dies. Your family is a team, with each person playing an essential role. Is there room to collaboratively decide who is going to do which household age-appropriate tasks? Some examples are:
 - Helping with cooking/heating food up/ ordering food in
 - Putting dishes away
 - Doing laundry

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- Feeding/walking pets
- There is a balance between (a) encouraging children to feel useful and needed and (b) reminding children that they are still kids and not responsible for the burden of caretaking.

6. Finding time for your kid to still be a kid/teen

• When kids lose a parent, they often feel different from their peers. It will be important for them to still have outlets for play, creative expression, and social connection.

7. If it feels safe and authentic to do so, talk about and remember the person who died

 Talking about and remembering the person who died can be an opportunity to continue your child's relationship with their parent who died in the present day. It's okay to say the person's name and share what you remember about them. By bringing up their parent, you often give children and teens permission to share their feelings and memories. Sometimes, children and teens find comfort in continuing their relationship with their parent who died in other ways, such as visiting their gravesite, spreading their ashes, writing them a letter, lighting a candle, and sharing a favorite meal. The key here is not to force anything – two things can be true at the same time; it is okay for you to bring up these topics, and it is also okay for your child to choose whether or not they want to engage.

8. Consider possible "grief" days for your child and family:

- Birthdays
- Holidays
- Death day
- Caregiver specific days (Father's Day, Mother's Day)
- Caregiver specific school events (father-daughter dance)

As children grow and develop, their grief will grow and change with them. Their understanding and curiosity about what happened to their parent will likely shift; they may have the same questions, different questions, or more questions. 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?"

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Infancy (O-12 months) & Toddlerhood (1-3 years)

As children grow and develop, their grief will grow and change with them. Their understanding and curiosity about what happened to their parent will likely shift; they may have the same questions, different questions, or more questions. 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 do not have the cognitive skills to understand the concept of permanency; thus, they do not yet understand death as something permanent and irreversible. 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.	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. 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.



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 \rightarrow 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 e 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.



Preschool-age (3-5 years)

How	children	understand	death

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 \rightarrow 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
 - "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."
 - 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."



Elementary school-age (5-8 years)

How children understand death	How children might respond to death
Children at this age naturally begin to express curiosity about death (regardless of if they've lost a parent) and may ask many "why" questions.	Children at this age will likely have many questions, worries/fears about death, bodily safety, and health.
They are often concerned with justice and fairness. They may express feeling the death is "unfair," in some cases they may describe wanting "revenge."	They may verbally share that they are "fine" or may look like "nothing is wrong" though you may see their distress in bodily aches and pains or trouble with their schoolwork/paying attention, or increased perfectionism.
Developmentally, they view the world through their eyes, meaning it is common for children at this age to believe that their thoughts/actions caused the death to occur.	Some children may appear sad or withdrawn, while others may show their distress through irritability, anger, or anxiety.
By age 7, children begin to understand that death is permanent and irreversible.	Children may also express denial that the death occurred or disbelief that it "couldn't be true"



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.
- Offer accurate information to your child when they express curiosity or confusion about their parent's death.

Gently remind your child:

- "It is so sad Dad died...Dad loved you so much and did not want to die."
- "I know you want mom to come back...I want Mom to come back, too. But remember, when mom died and her body stopped working, that means she won't be coming back. We can always love Mom 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 \rightarrow helping a child understand who will care for their day-to-day tasks (i.e., who will pick them up from school, cook their meals, and put them to sleep)

Provide outlets for children to express themselves and have developmentally appropriate control

- Can they choose their extracurricular activity
- Can they choose what chores to complete around the house

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.

At this age, as children begin to socialize more with peers and navigate social conflicts, it could be helpful to explore kids' grief support groups in your area. While most children do not need individualized therapeutic support, it can be incredibly healing for kids to connect with other people their age who have shared experiences.

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 something called cancer. This is a very different type of sickness than getting a cough or having a tummy ache. Cancer happens when people's bodies grow bad cells called cancer cells. Cancer cells can make people very, very sick and can even sometimes make them die.

• Why did they have cancer?

 Most of the time, no one knows why someone gets cancer. It can be hard to not know why someone gets very sick. What do you think?

A child may wonder about this because they are worried that they or someone else they love will get sick or die.

• Do I have cancer? Will I die? Will you die?

- I don't have cancer and you don't have cancer. Remember that cancer sickness is different from being sick with a cough, cold, or stomach ache – we can't catch cancer like a cold. Our bodies are healthy.
- Every living thing eventually dies, and you and I are healthy. We will not die for a very long time.

• 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 take special medicine and get help from special doctors to try to get rid of these bad cells called cancer.
- Mom had surgery to take out as much of the cancer as possible. Surgery is when doctors use special tools to try to fix their body. Mom was sore after she had surgery, but she didn't feel any pain while the doctors were giving her surgery. That's why she had a scar/her chest looked different/her arm looked different/she couldn't play as much. It helped Mom by helping her live longer with her cancer/making her pain better, but the cancer was too big and strong, and the surgery was not able to kill all of the cancer cells in her body.

• 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 medicine or treatments they have.
- Lots of smart scientists and doctors are making better and stronger medicine every day. Hopefully, someday soon, there will be medicine that is stronger than any 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.

Cancer that runs in families

- Some types of cancers are more common in some families. Mom's cancer was not one of these. Just because she had it does not mean you or anyone else will have it.
- Mom's cancer was one of these, but that doesn't mean anyone else in our family will definitely get sick with cancer. There are a lot of things we can all do to help keep everyone healthy, like going to the doctor for checkups every year and getting special tests.
- People don't get this kind of cancer until they're much older than you are. When you're a grown-up, you can get this special kind of test, too, to help keep you healthy and know what's happening inside your body.

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.
- What do you think?
- We can't always know what will happen, but what I do know is that you will always be safe, loved, and taken care of.

Middle childhood (9-12 years)

How children understand death	How children might respond to death
At this age, children fully understand what death, dead, and dying means. They understand that death is permanent/irreversible (the person cannot return/come back to life) and is universal (that all living things and people die). They may also have a good sense of when adults are being honest with them or when parts of the truth are being hidden or "sugar- coated" for their benefit.	As children begin to enter early adolescence, they will 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). This is also a time when children may begin to enter puberty, which could also bring up feelings of distrust/fears of being abandoned. 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 children want to know more than others at this age. Some children this age 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 children what they think. They may understand more than you realized, or they may surprise you with an explanation that isn't quite right. 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.

Gently remind your child:

- "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"

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



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

Provide outlets for children to express themselves and have developmentally appropriate control

- Can they choose their extracurricular activity
- Can they choose what chores to complete around the house

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.

At this age, as children begin to socialize more with peers and navigate social conflicts, it could be helpful to explore kids' grief support groups in your area. While most children do not need individualized therapeutic support, it can be incredibly healing for kids to connect with other people their age who have shared experiences.

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 sickness 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.

• 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 the world around us, like cigarette smoke or too much sun without wearing sunscreen. Often, cancer happens without anyone knowing why.
- It can be hard to not know why someone gets very sick. What do you think?

• Do I have cancer? Will I die? Will you die?

- I don't have cancer and you don't have cancer. Remember that cancer sickness is different from being sick with a cough, cold, or stomach ache – we can't catch cancer like a cold. Our bodies are healthy.
- Every living thing eventually dies, and you and I are healthy. We will not die for a very long time.

• 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 special treatment from special 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 didn't feel any pain while the doctors were giving her surgery. That's why she had a scar/her chest looked different/her arm looked different/she couldn't play as much. 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.

Chemotherapy

 The doctors gave Mom very strong medicines called chemotherapy. These medicines are for fighting cancer cells. She had to go to the doctor a lot to get chemotherapy. Because the medicine 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.
 Radiation uses special machines that make 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, the medicine people take to try to get rid of cancer cells is very, very strong and can also make them feel sick.
- Medicines like chemotherapy/treatments like radiation fight cancer by killing cancer cells. Sometimes, they also kill other healthy, fastgrowing cells like the cells that grow our hair and the cells inside our stomach...which is why people who take cancer medicine often lose their hair, feel sick, or get really sick a lot.
- Did you see Mom feel sick? 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 medicine or treatments they have.
- Lots of smart scientists and doctors are making better and stronger medicine every day. Hopefully, someday soon, there will be medicine that is stronger than any 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.
- What do you think happened?

Cancer that runs in families

- Some types of cancers are more common in some families. Mom's cancer was not one of these. Just because she had it does not mean you or anyone else will have it.
- Mom's cancer was one of these, but that doesn't mean anyone else in our family will definitely get sick with cancer. There are a lot of things we can all do to help keep everyone healthy, like going to the doctor for checkups every year and getting special tests.
- People don't get this kind of cancer until they're much older than you are. When you're a grown-up, you can get this special kind of test, too, to help keep you healthy and know what's happening inside your body.

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.
- What do you think?
- I wonder about that, too. Sometimes, it helps me to think about (share your beliefs or things that bring you comfort).
- What helps you when you feel upset or worried about this?
- We can't always know what will happen, but what I do know is that you will always be safe, loved, and taken care of.

Adolescence (13-18 years)

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 "sugar- coated" 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.

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Concerning grief reactions & when to seek support

While all grief reactions/responses are normal responses to unimaginable loss, there are certain grief reactions that warrant additional support and care. If any of the above behaviors or expressions of emotions interfere with a child's functioning/development – such as interfering with their hygiene, eating, sleeping, family relationships, school performance, and peer relationships – your child deserves professional mental health support.

Additionally, if at any time, your parent instincts/senses pick up on your child experiencing any of the below, professional support should be sought as well:

- Severe depression → giving up on school, extracurricular activities, withdrawal from friendships, and significant shifts in eating more/less and/or sleeping more or less
 - Prolonged feelings of guilt or hopelessness
- Self-harm (i.e., any action your child engages in to intentionally harm themselves/their bodies)
- Thoughts/statements about death, dying, and/or suicide
- Impulsive, reckless, or aggressive behaviors that put your child's safety or the safety of others at risk
- Substance or alcohol misuse (i.e., any other form of numbing)
- Severe anxiety that inhibit a child's functioning (i.e., that prevent the child from attending school, staying in school, maintaining relationships with others, navigating activities of daily living)

When seeking mental health support, we encourage you to first speak with your child's pediatrician to share with them your concerns and also ask for their recommendations/referrals for therapists. We encourage you to seek therapists who have experience and expertise in working with children and adolescents in addition to having training in grief/loss. If you're interested in finding group-based support, the below resource from the National Alliance for Children's Grief could be a helpful place to start:

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

If you're ever immediately concerned for your child's well-being or safety, please know that you can always reach out to one of the below resources that are available 24/7.

If you are in the US:

- Call 988
- National Suicide Prevention Lifeline (Chat Available): 1.800.273.TALK (8255)
- Crisis Text Line: Text CONNECT to 741741
- The Trevor Project (LGBTQ+): 1.866.488.7836 (Text & Chat Available)

If you are in the UK:

- Call 116 123 to reach Samaritans
- Text "SHOUT" to 85258 to reach the Shout Crisis Text Line.

Taking care of you

One of the biggest gifts you give your child as they grieve is to take care of yourself. Just like kids look to their caregivers for examples of how to do anything else, they'll also learn from your example whether or not it is okay to ask for help and receive it. Seeing you lean on others for support, talk openly about your feelings and memories, and do things that bring you comfort or joy will help your child learn to do the same. You do NOT need to "have it all together" – your child does not need a perfect parent (they don't exist). They just need you to be open to their emotions and to your own needs as you navigate through grief together.

Support for you can look however you need it to – whether that be talking with family or friends, you feel comfortable sharing your grief with or seeking a support group that offers a shared perspective on the wide range of what's "normal" to experience as you grieve and care for a grieving child.

You also deserve individual therapeutic support if that is something you're interested in pursuing. Your grief deserves tending, too as well. As hard as it can feel (and as hard as it is) to ask for help – can friends, family, and/or coworkers support you with day-to-day tasks like meals, carpooling, or laundry? The answer might be no, and that's okay, too – if you take anything away from this guide, we hope that it's the invitation to create space for your needs as you care for your child's.

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 <u>explaining to a young child that</u> someone has died, preparing for funerals, <u>understanding how to help</u>, and <u>how children understand death at different developmental ages</u>.



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 → <u>www.Griefshare.org</u>

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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 → <u>www.lifeofdad.com</u>

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.

- <u>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</u>
- <u>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</u>
- <u>https://www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer/dealing-with-parents-terminal-illness/kids-understanding-death.html</u>

Cancer.Net from the American Society of Clinical Oncology

(<u>www.cancer.net</u>)

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 (<u>www.nacg.org</u>)

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

- <u>https://indd.adobe.com/view/246ac201-44b2-4dd2-b7cb-b53c2094b64b</u>
- <u>https://indd.adobe.com/view/e66b0d18-90f8-4edc-a046-e1cd1b3bd859</u>

Sesame Street Workshop

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

<u>www.sesameworkshop.org/topics/grief/</u>

Camp Kesem

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

• <u>www.kesem.org</u>

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/

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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

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

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)



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https://elunanetwork.org/

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

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



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

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

<u>https://judishouse.org/wp-</u> <u>content/uploads/2023/02/Commongriefreactions-2023.pdf</u>

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

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

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

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

https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families_s/FFF-Guide/Children-And-Grief-008.aspx

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

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