



Your Conversation Starter Guide

For Caregivers of a Child with Serious Illness

How to start talking with a child who is living with a serious illness about the health care that is right for them.



the **conversation** project

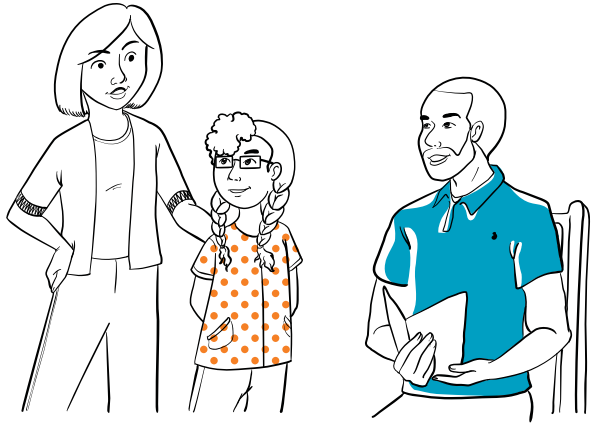
The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected.

Talking about the kind of health care we want through the end of life can be hard. It can be even harder when a child we care for is living with a serious illness.* But it's very important to talk with your child to learn about what matters most to them. If you talk about it, and understand what their wishes are, you will be better able to make health care decisions for them.

Having this talk with a child who is seriously ill is different from having the same conversation with an adult. It can be difficult (or not possible) for a child to share their wishes. And it can be very difficult as a caregiver to accept that a child's time to live may be shortened or painful.

We created this guide to help you talk with your child, understand what matters to them, and feel some comfort knowing that you can help guide their care and honor their wishes. Keep in mind that a conversation can vary depending on the age of the child, the type of illness, and their current treatment options.

* A serious illness is a health condition that limits a child's daily function or quality of life, and may shorten their life.



We'll help you take it step by step.

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If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.)

Completing it on your computer will create a digital document that you can easily share with others.

STEP 1

Prepare

➤ Should I talk to my child about their health care wishes now and through the end of life?

If you're worried that having a conversation with your child about their serious illness might make a tough situation even worse, you're not alone. Having this talk is not easy. You may feel:

- Worried that the conversation will scare your child
- Concerned that your child will lose hope
- Unsure how much your child should know about their illness
- Afraid that talking about suffering or death will somehow make it happen
- Worried that others in your family won't support you
- Uncomfortable because talking about death and dying isn't part of your culture

➤ What's your biggest fear about having the conversation with your child?

These thoughts and feelings are normal. But talking with your child won't harm them or make their illness worse. It can be helpful for everyone.

Children might sense they are seriously ill or dying — even if no one is talking about it. In fact, your child might be waiting for you to say it's OK to talk about their feelings.

And, research shows that parents who talk about death with their child cope better after their child dies, and they have fewer regrets. But those who don't talk with their child may have feelings of regret.*

* Kreicbergs U, et al. Talking about death with children who have severe malignant disease. New Eng J Med. 2004;351:1175-1186.

- Talking with your child about their illness and what matters to them can help you advocate to get the care that is right for them.

You may have already talked about what's important to your child if they had a previous hospital stay or health procedure. You know your child and how to talk to them. Although it may be different now when talking about and preparing for possible end-of-life care, you can trust yourself.

The goal is to find out what's most important to your child, including:

- What makes your child uncomfortable? Confused? Angry? Sad?
- What does your child want their doctors, nurses, or others on the health care team to know?
- What can you do to make sure your child feels safe? Comfortable?
- If your child is in the hospital or another health care facility, do they want to have their favorite comfort item, such as a stuffed animal, a favorite piece of clothing, or a picture of a favorite place?

- Think about what you need to have the conversation.

To get started, it helps to think about what you need to prepare for the conversation.

Here are some ideas:

- You may need support of co-parents, grandparents, or other family or friends who may not always agree on the best path to take. You can ask them to talk about their own beliefs, to help sort individual feelings and questions first. And then ask them to help you focus on what matters most to your child. It will make it easier to talk to your child when thoughts and feelings are shared among people who matter in their life.
- What do you expect your child to say? You can think through answers or responses before you talk.
- Think about how you hope the conversation will go. For example, do you want more information about what your child is thinking about a certain thing?
- Think about whether there is any additional information you need before talking. Do you need medical information from the health care team? Do you have questions for an interpreter or other support person?

- > What do you need to think about or do, so you feel ready to have a conversation with your child? What will make it easier for you to get started?

FOR EXAMPLE It may help to talk to those you trust and those who have close relationships with your child: your co-parent or your child's sibling; a trusted doctor, nurse, or other member of the health care team; a counselor or therapist; a spiritual or faith advisor; or a favorite teacher.

- > What do you need to do to help your child feel ready to have a conversation?

FOR EXAMPLE You can think about choosing a time and place where you and your child are able to focus on having the conversation.



STEP 2

Talk

Now that you've thought about talking, it's time to start.

We can't tell you the best way to have the conversation with your child, because it's different for every child and family. But we can tell you what works for some children, so you can make the best choices for your own child. Here are some things you can do that may be helpful.

➤ Tell your child that you can handle the conversation.

To help reduce your child's anxiety, it can help to start by telling them it's OK to talk honestly. You could say, "It is sad and hard for me to talk about this with you because I love you so much and want you to be all better. But it's also really important so you can share what you are thinking and feeling. I want you to know you can tell me anything."

➤ Let your child steer the conversation.

Allow your child to lead the conversation based on their own thinking, reasoning, and developmental abilities. Listen carefully, and only answer their questions as they ask them. You can also ask them how much they know about a certain topic before responding. That way you can give them an answer that is proper for their age and respects how much information they want. The important thing is to be open to your child's questions, so they feel comfortable asking.

➤ It's OK if your child doesn't want to talk for long — or at all.

If you have a two-minute conversation, and your child stops talking — it's OK. They may just need time to process what you've said. Follow their lead. These conversations can happen over many shorter talks, over time. The important thing is to let your child know you'll be there whenever they do want to talk.

➤ If your child asks if they are dying, try asking them a question.

To answer the question, it helps to understand what they know — or don't know — first. You can turn the question back to them by saying, "Do you think you're dying? What makes you think about that?" Then you can use their answers to guide your conversation. It's best to give just enough information to answer honestly, but in a way that is proper for their age. For example, you can say, "Dr. Jones doesn't think we have any more medicines to treat your cancer."

➤ If your child doesn't speak, look for other ways to communicate.

Even if your child can't speak because of their age, condition, or abilities, it may be possible to communicate with them about their wishes in a different way. For example, you can let them guide you with nonverbal cues like face expressions or gestures. If possible, you could ask them to draw a picture. You can also think through what would matter most to them yourself or with a trusted support person. You know your child best.

➤ Here are some ways you can start the conversation.

- Talk about the loss of someone close to your child — a grandparent, another family member, a pet, etc. For example, you can say, "Remember when Grandpa died?" Or, "Remember when our dog, Scout, died?"
- If you and your child believe in heaven or an afterlife, ask them what they think about it. You can say something like, "Do you ever imagine what heaven is like?"
- Ask questions that can't be answered with a "yes" or "no."
For example: "How do you think your treatment is going?"
- To talk about death, use storytelling to help start the conversation.
For example, you can try showing your child an appropriate book, movie, or cartoon with a character who dies. Then, see what your child says or ask questions, like, "What did you think about the story?"

➤ Once you have started the conversation, here are some things you might want to talk about with your child.

- What would you like me to tell your doctors and nurses about how you want to be treated?
- What do you want me to tell them about how you don't want to be treated?
- What three things do you want your doctors and nurses to know about you?
- What makes a day good for you? What makes a day bad?
- What food do you like best? What food do you not like?
- Who would you like to come visit you?
- If you're very sick and may die, would you want to be in the hospital or at home?
- Are there people you would like your special things to go to?

- Ask your child: What are three important things that you want your friends, family, and health care team to know about you?

Things I really like:

Things I really don't like:

- You can also help your child create a list of “Things That Matter to Me” and post it for your child’s health care team to see.

For example:

- Please don't talk down to me.
No baby talk!
- Please don't talk about me like I'm not here.
- Please don't ignore me because I don't speak.
- Please bring someone who speaks my language.
- Please don't talk loudly.
- Please answer my questions... all of them. And be honest!
- Please don't turn on the light when I'm asleep.
- Please ask before touching me.
- Please tell me who you are if I don't know you.
- Please knock before coming into my room.

- What if I need help?

- There may be times when you will feel more comfortable talking to your child's health care team before you talk to your child. You may need to ask them questions first. That is OK!
- You can always ask someone on your child's health care team for help. You can say, “I'd like to talk to my child about what's happening, but I'd like some advice and help. Is there someone [a doctor, a nurse, a social worker, a chaplain, a patient advocate] who could help me?”
- You may want to ask a member of the health care team or a trusted friend, spiritual or faith advisor, or other trusted community member to join you when you begin this conversation with your child.
- There may be times when you can't answer a question from your child, and that is OK too. You can be honest and tell your child you're not sure of the answer, but you will find out.

- It also may be important for your child to start talking and keep talking with others on their care team or other trusted friends or family members.

Sometimes your child may need to process this with others. Encourage them to talk to those they trust on their own.

STEP 3

Advocate

Once you know what's on your child's mind, or have thought about what would matter most to them if they are non-verbal, you'll be ready to share your child's wishes with their care team. As an advocate for your child, you'll help to make sure the health care team is ready to respect those wishes as much as possible.

Here are some things you can do to help you advocate for your child — or help them advocate for themselves.

- Share some information with the health care team about what matters most to your child, and your own concerns as their caregiver.

You can start by telling the health care team you'd like to talk to them about what matters most to your child. If your child made a list of "Things That Matter to Me," you can post that list in the room if they're admitted to the hospital, or bring it with you to appointments. Ask your child's health care team to read or listen to the list. Then, use it to have a conversation with them. You can ask your child if they want to be part of this conversation.

It's helpful to remember that the health care team also wants what is best for your child. Sometimes, your child's wishes might not be possible or may conflict with good medical care. For example, your child may not want any more blood draws or other tests, but they may be needed for their treatment. When you tell the health care team about your child's concerns, they may be able to change their approach. For example, they may be able to do tests at the same time instead of many separate blood draws. It's helpful if you consider your child and family part of the health care team, working toward the same goals.

If your child's condition gets worse, it's also important that your child's health care team knows how much you want to know about what is happening with your child. And, if being informed is part of what matters most to your child, make sure they are part of these conversations.

➤ Here are some ideas for wishes and preferences you can share.

- My child communicates with others, to share what they are feeling and thinking, by _____.
- I want to know about these parts of what is likely ahead with the illness: _____.
- I do NOT want to know about these things: _____.
- My biggest fears and worries about my child's condition are _____.
- What matters most to me for my child and my family is _____.
- If my child's health condition worsens, here are the most important goals for my child and my family: _____.

➤ If you have questions for the health care team, ask them.

No question is too small, so ask — and keep asking until you have answers that make sense to you and your child. You can start by saying, "I have some questions I'd like to ask you about my child. Is now a good time?"

Here are some examples of questions you might ask:

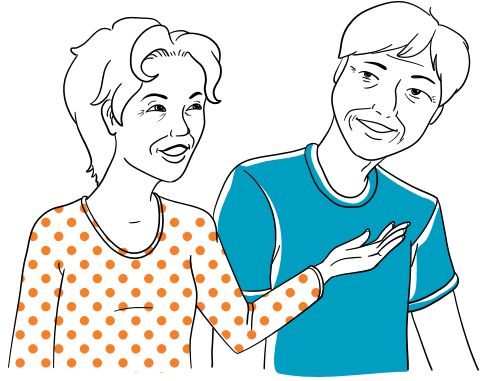
- Can you explain what you mean when you say _____?
- Here is what I understand about my child's illness. Is there anything else I need to know?
- Who is part of my child's care team? (Example: palliative care doctor, child life specialist)
- What should I look for in the next [hours/days/weeks]? And what decisions might we have to make?
- Could you help me understand the best and worst scenario that might happen? What is most likely to happen?
- How is this illness going to change over time? How are things changing now?
- If my child may die from this illness, how will it likely happen? For example, will there be an infection? Will there be pain?

> It's also important for you to have conversations with others who care for your child – such as other family members, friends, or clinicians — so everyone can support your child and you.

Most important, you should keep talking with your child's health care team to guide how decisions are made. You'll want to make sure that your child's wishes are kept in mind, even when they can't share them. You can read our [Guide for Talking with a Health Care Team](#) for more information.

If your child's doctor, nurse, or other clinician is not available, you could try to talk to a patient advocate, hospital chaplain, local death doula, hospice provider, or social worker.

Since your child's wishes could change over time, it's a good idea to talk with them regularly about what matters most. Share any new information with their health care team.



STEP 4

Learn from Others

We know this is a difficult time for you. Remember you are not alone. Here is some advice from parents and caregivers who know what it's like to cope with a child's serious illness.

TALKING ABOUT A CHILD'S DEATH.

"Over two months, my husband and I sat down and talked together about our care goals for our daughter. What would 'quality of life' mean to her and what it would mean to us? What were treatments she wouldn't want done to extend her life? How would we know when she was ready to die? And we trusted that we would know it.

When a parent asks, 'Should I have the conversation with my child?' they sort of already know they should. This is the scariest thing the parent will ever have to do — but it's so important."

- Blyth, whose child died at 2

"It's important to remind parents that just having this conversation doesn't mean you will make death come faster. I've seen families think that just because they have the conversation, their child will give up and die.

In Austin's case, we said, 'The doctors are going to try their very best to find a cure, but they may not be able to find a cure in time to beat this disease. The disease might get worse. But the doctors have promised they will do their best to keep you free from pain.'"

- Dianne, whose child died at age 14

COPING WITH YOUR OWN FEELINGS AS A PARENT.

"Sometimes my conversations with parents and children might go like this:

Parent:

'I don't want him to know that I'm sad.'

Me to parent:

'Well, you are sad. You're sad because the doctors can't cure his disease, there's no more medicine that makes sense. You're sad because he's going to die so young.'

Me to child:

'Why are you afraid to have your mom cry?'

Child:

'It will make her sad that the doctors can't make me better.'

Me to child:

'She already knows this and she's already very sad — she loves you so much. I wonder if you talk about this, it might make you feel better.'

That often works. Tears are OK."

- Kathy, an experienced pediatric nurse

CONVERSATIONS PROVIDING A SENSE OF PEACE.

"Last week, I heard a parent say she was at peace with her child's death, as much as she could be. She said that he died in his own way, including where he wanted to die, and how alert he wanted to be. This child slipped away quietly while no one was paying attention and the mom just thought, this is exactly what he would have wanted. She believed that he was trying to protect her. He didn't want her to have to say goodbye in that moment, so he just slipped away when no one was looking."

- Blyth

FOLLOWING YOUR CHILD'S LEAD.

"In many cases, a child's health may seem to get better and worse; it may even seem like they are near death, but then improve again. I had to have many conversations with Austin because it looked like he was going to die many times. I asked Austin questions to hear what his own understanding was. I asked, 'Do you think the doctors will be able to cure you?' And he said no. And I said, 'I think you're right.' It was led by him."

- Dianne

"As parents, when children want to speak about dying, we want to comfort them and tell them they'll be OK. We need to let them explore the topic of death just like any other topic. If a child brings up the subject, parents should follow this brave lead.

When Lydia brought up the subject of death, she'd been battling cancer for a year and a half. She asked, 'Do you think God would let me see myself as a teenager if I died now?' 'Yes,' I said. 'Just ask...'

That's when I asked more questions. By the end of the conversation, Lydia had decided where she wanted to be buried, the color of her coffin, and other special things she'd like done at her funeral.

Then the door was open for talking over the last six months of Lydia's life. I told her that I'd never want to live without her, but I would be able to — just like we could keep living when my mother died. She told me when she felt her time was coming to an end, and I told her that I thought Grandma and God would greet her on the other side."

- Paula, whose child died at age 9

The role you play in your child's care is very important. These conversations can help you learn what matters most, and help you feel confident in your decisions. You can return to this guide whenever you need help having another conversation, so you can help them get the health care that is right for them.



Find more information, including our [Conversation Starter Guide](#), blog posts, personal stories, and more tips for talking on our website, theconversationproject.org

SPECIAL THANKS TO

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