



The Art of Parenting While Sick helps parents with chronic health conditions feel seen and supported and find solidarity in a global community. To learn more, visit parentingwhilesick.com

HOW DO I...

talk to my child about my chronic health condition?

Advice for Parents and Caregivers

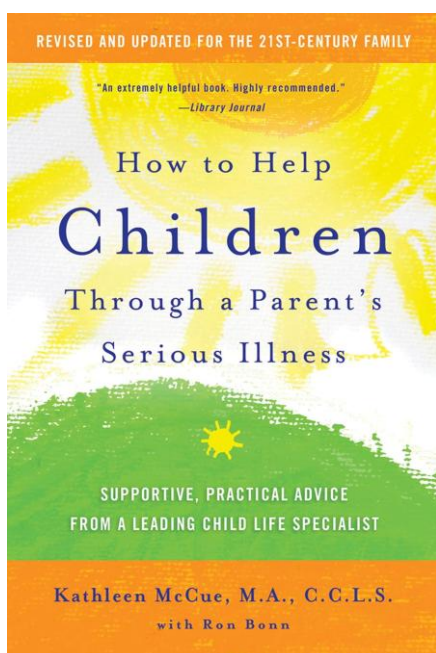
There are many reasons you might need to talk to your child about your health:

- you were recently diagnosed with a **new condition**
- your existing condition is **flaring up**
- your existing condition is **worsening**
- your condition was in remission but has **come back**
- you are starting a **new treatment or using a new device**



You might have the instinct to hide information about your health from your child so you don't worry them.

However, creating an **open and fluid dialog** is key to helping your whole family understand what you need so they can support you, anticipate what you can and cannot do and adapt accordingly, and be prepared for any unexpected hospitalizations, medical emergencies, or surgeries.



Kathleen McCue, the author of *How to Help Children Through a Parent's Serious Illness*, is a leading Child Life Specialist who worked with hundreds of families at the Cleveland Clinic. Over the years, she consistently found that **children whose parents communicated honestly and consistently about their condition fared much better and had fewer behavioral issues than children whose parents didn't.**

Why you should talk to your child ➡

Why you should talk to your child

If you don't talk to your child about changes to your health, you **run the risk that they might hear about it anyway** from a family member, a friend's parent, or even you if you're talking about it and don't think they can hear you.

When you are **up-front, honest, and open** with your child, you show them they are a respected and important part of the family, that you take their feelings and opinions seriously, and have faith they can handle a difficult situation. You also establish yourself as their conduit of information which lowers the likelihood they'll get online and upset themselves reading inaccurate or misleading information.

BEFORE you talk to your child



Be sure you're ready. Practice what you're going to say a few times with a friend, family member, therapist, or by yourself. You might very well be processing your own anxiety, sadness and frustration and find yourself tearing up while you try to talk about it. If this is the case, it's a good idea to wait a few days until you can talk more calmly and focus on reassuring your child.



Write down notes. Take notes on the steps in the script below so you can be sure you say everything you want to. As you'll see, each step of the script ends with a point you can make to comfort your child. Writing down notes ahead of time can help you remember to blend factual information with reassurance.



Think about logistics. First, decide where the conversation will take place. The living room or kitchen are typically good, neutral spots. Then, decide who's going to be there. If you have more than one child, try to talk to them all at the same time. If you have an adult child living outside the home, tell them as soon as possible before or after your conversation with the rest of your children.

It's a good idea to have the conversation over the weekend to give your child time to process. If you attempt to squeeze in an important conversation before school or at the end of the day, you run the risk they will be rushed, cranky, or hungry and that there won't be enough time for them to ask any questions they may have.

5-step script ➡

The 5-step script

You can easily adapt this script to talk about a new diagnosis, a flare up, a worsening condition, new medication, and other updates

1. Say what's going on.

- Keep your language simple, clear, and straightforward.
- Name the body parts where your condition is manifesting. For young children, you can use a visual aid like a pamphlet, book, or doll.
- Describe your symptoms in brief.
- Explain how your doctor diagnosed the condition.
- Reassure your child that many people have the condition, your doctor is an expert at treating it, and your symptoms are typical of the condition.

"I went to the doctor this week and she said I have diabetes. That means I can't make a chemical called insulin which our bodies need to control our blood sugar. Blood sugar is where we get energy from. That's why I've been so tired lately. She doesn't know why I developed it now but almost half of people are diagnosed around my age. She diagnosed me after checking the level of sugar in my blood.

Almost 600 million people around the world have some kind of diabetes! That's 1 in every 9 people. My type, which is called type 1, is more rare. Around 10 million people have it. That's still a lot of people! And almost all of them live full, healthy lives."

2. Tell them what the treatment plan is.

- Describe any new medication.
 - Say when and how often you'll take it.
 - Describe how you'll take it, for example, as a pill, a shot, or through a pump. You can show them the medication or device and let them touch and inspect it.
 - Describe how it works in simple terms.
 - Reassure your child that a lot of people receive the same treatment.

"I'm going to start taking insulin every day to keep my blood sugar at the right level. I'm going to get it through a pump that I'll wear and move around my body every few days. See? Here it is on my hip. I just started using it and it's releasing insulin into my body right now.

The pump is connected to a glucose monitor which helps track my blood sugar in real time and adjusts the insulin automatically. Look at the app on my phone. Isn't that amazing?

And I'm definitely not alone. Almost 150 million people around the world take insulin."

5-step script (continued) ➡

The 5-step script (continued)

3. Tell them you are in good hands.

- Talk about your doctor, nurse, and any other healthcare professional who is helping you and add any details that might help your child picture them so they can imagine who is caring for you.
- Reassure your child that doctors deal with your condition frequently.

“My doctor is an endocrinologist. She helps thousands of people with diabetes every year. Her name is Dorothy, and I saw she has a big fish tank with tropical fish in her office. If you come with me some time you can see them, too.”



4. Talk about how your condition will affect you and them.

- Describe anything you will be doing differently such as staying at home more, eating differently, sleeping more, and so on.
- Describe any changes to the family routine.
- Reassure your child that you'll keep them updated on any other changes.

“I will be paying more attention to what I eat and eating less sugar. That means I might sometimes eat slightly different meals than the rest of you. I'll also be using that pump I showed you and testing my blood sugar. I'll show you some time when I'm doing it.

I may have a few more doctor's appointments later this month so your aunt Rachel might take you to soccer a few times. I'll keep you posted.”

5. Say what you need from them.

- If you are unable to do any chores like gardening, cleaning, walking the dog, or cooking and need their help, be specific about what you need.
- Set any guidelines that will help you manage your condition. For example, if you are immunocompromised, you might ask your child to wash their hands whenever they come home from the outside world and not to bring over friends who are sick.
- Reassure your child that you are managing your condition, they don't need to worry about you, and the best thing they can do is enjoy their lives.

“I don't think too much will be different. I want you to know I'm in good hands and learning to manage my condition. I'm going to have this for a long time and there will be times when I'm healthy and times when I'm not.

Even if I'm not feeling well, you never need to feel guilty for focusing on school and soccer or having fun with your friends. The best thing you can do for me is to enjoy all those things.”

Adapt the script by age ➡

Adapt the script by age

Children 5 and under

Why you need to adapt your script At this age, children don’t have a clear sense of cause and effect and tend to be egocentric in their thinking. That means they might worry you got sick because they spilled their milk or didn’t clean up their toys.

For that reason, be sure to emphasize that nothing in particular caused your condition. You will also need to simplify the message.

What you can say *“I am having a health problem. I just learned I have diabetes. A lot of other people have it, too.*

The doctor is giving me the same medicine those other people take. It’s called insulin.

You can’t catch it, and no one caused it. It just happened.

You can give me hugs and kisses in the next few days to help me feel better.”

Pre-teens and teenagers

Why you need to adapt your script A lot of the time, mature pre-teens and teenagers will want to know more about the facts and science behind your condition.

If they are interested, you can involve them more heavily in your treatment.

What this looks like You could:

- bring them to a doctor’s appointment with you where the doctor can explain your condition in more detail
- watch videos online about your condition together
- plan an online or in-person fundraiser for a foundation that specializes in your condition (see below)

Ideas for fundraisers:

- host a(n)
 - lemonade or hot cocoa stand
 - dance marathon
 - ice cream social for the neighborhood
 - trivia night
- start a campaign on social media
- ask a fit friend of the family to run a marathon for your foundation and support their campaign



Prepare for your child’s reaction ➡

Prepare for your child's reaction

- **Make it clear that any kind of feeling is normal and ok .** During the conversation, your child might cry, get angry, or seem nonchalant. You can say, *“We can have all kinds of feelings when someone is sick – we can feel angry, sad, annoyed, lonely, worried, or like things are not that different. There is no right or wrong way to feel about this.”*
- **If your child says they don't have any questions,** you can get the ball rolling by asking questions like, *“How do you feel about what I told you? Is there anything you want to know more about? Is there anything you are worried about in particular? How can we all take care of each other right now?”*
- **If your child asks you a question and you don't know the answer to it,** write it down and say, *“Great question. I don't know the answer to that. I'll ask my doctor at our next appointment.”* Then be sure to ask your doctor and report their answer back to your child. That will help them feel like their questions are valuable and like they are helping with your treatment.
- **When the conversation feels like it's run its course, wrap up** by saying something like, *“You can come to me with questions any time or if you just want a hug, I'm here for that, too.”*
- **Then end by doing something pleasant** like cuddling, reading a book, or playing outside with young children, making a sundae with school age children, or watching a movie or going on a walk with a teenager.

