



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...

help my family handle a hospitalization?

Advice for Parents and Caregivers

Chronic health conditions are a leading cause of hospital admissions, and many people living with them will experience an unexpected hospitalization at some point.

If you have a condition that can cause a medical emergency leading to an unexpected hospitalization, for example:

- an adrenal or thyroid crisis
- anaphylaxis
- an asthma attack
- cardiac issues
- a kidney infection
- pneumonia
- a seizure
- sepsis, and so on



it is helpful to come up with a plan ahead of time for what you will do if that happens.

One of the most important things to do is to train 2-3 trusted adults who can step in and take care of your children in the event you are in the hospital.

You can use the 5-step script below along with the **checklist for hospitalizations** to help prepare your support network for what to do if you are unexpectedly hospitalized.

5-step script ➡

The 5-step script

This script can be used by a partner, family member, friend, or neighbor or any other trusted adult who is caring for your child while you are in the hospital.

1. Explain why their parent is in the hospital.

- Say what happened. Explain how their parent's condition caused the current issue.
- If you know it, give a loose estimate as to a timeline for when the parent will be home.
- If the child has been to the hospital where the parent is (for example if they were born there or went to the ER for an injury), let them know it's the same one. Being able to picture where their parent is can be comforting.
- Reassure the child their parent is in good hands.

"As you know, your mom has sickle cell anemia. That means sometimes the sickled cells in her body can clog up her blood vessels. Earlier today, that happened and it made it hard for blood to get to her heart. Her chest hurt so she went to the emergency room.

They did tests and gave her medicine to help her blood flow normally again. She's already starting to feel better, but the doctors want to keep an eye on her until tomorrow then she'll most likely come home. Your mom is safe right now, and she's in good hands.

She's at the same hospital where you went when you cut your leg and needed stitches. Do you remember that?"

2. Say what treatment their parent is getting.

- Explain they need to be taken care of at the hospital (and not a doctor's office or at home) because they have access to special equipment, medicine, and tests there.
- Say what medicines they're taking.
- Reassure them that the treatment (medication, IV, feeding tube, oxygen etc.) is working.

"They are keeping her there because they are using special machines to track her blood flow and heart to make sure her body goes back to working like normal. They put her on a medicine called voxelotor that helps her body get rid of the bad cells and they are giving her water through an IV to keep her hydrated. The doctors say the treatments are working very well."

If this has happened before, you can add something like, "You've seen your mom be sick before and remember? She got better then, too."

5-step script (continued) ➡

The 5-step script (continued)

3. Tell the child a few details so they can imagine their parent safe in the hospital.

- Make it clear this issue can happen sometimes because of their parent's condition and doctors are experts at dealing with it.
- Say the parent is getting constant care from doctors and nurses even at night.
- Reassure child with any details that might soothe them like that the parent is getting regular meals and snacks and that they can rest and watch TV.

"This kind of issue happens all the time to people with sickle cell anemia, so doctors are good at treating it. Your mom's doctors and nurses are taking good care of her, and they are even going to come in throughout the night tonight to check in on her and make sure she's doing fine. Right now, she is resting in bed and getting ready for dinner. They're going to bring it to her on a tray."

4. Tell the child how their parent's hospitalization will affect them.

- Say whether people will visit or stay at the house.
- If they will need to sleep somewhere else, let them know as many details as possible about where they will be staying and for how long.
- Reassure the child there is a plan, even if it's loose. Describe any changes to the family routine including how they will get to school, sports, music, and extracurricular activities.

"You'll still go to school tomorrow. And after school, Diana's dad is going to take you to soccer practice. I'll pick you up afterward."

5. End by going over next steps.

- Say whether they will visit the hospital and if so, when, and whether they will call or videochat with the parent in the meantime.
- Ask what they want to do for the rest of the day. Having choices, even over something as simple as what to eat or what movie to watch, helps the child gain a tiny bit of control over what can otherwise feel like an uncontrollable situation.
- Tell them it's ok to feel sad or anxious and that it's also ok for them to go ahead and do normal things like their homework.
- Reassure the child you will let them know as soon as you have any updates.

"I've been texting with your mom, and I'll let you know as soon as she sends me any updates. I'm not sure if we'll visit her yet because she might not be there very long. We don't know the next steps yet, but I'll tell you as soon as we do. In the meantime, let's figure out dinner. Do you want pizza or Thai food? After we eat, we'll call her together. Then you can finish your math homework."

Does that sound good? How are you feeling about all of this?"

Updates and adapting the script by age ➡

Updates and adapting the script by age

Check in with the child a few times a day until the parent returns home. Even small updates will help the child feel more in control of the situation, for example, if the parent:

- gets downgraded from the intensive care unit or emergency room to another ward
- moves to a new room
- has a good test result
- starts a new medicine
- takes a walk around the hall or outside
- has a new roommate

Children 5 and under

Why you need to adapt your script

If you are talking to a child who is 5 or younger, you can follow the steps above but keep it short and simple.

Try to stick to 5 or 6 sentences.

What you can say

“Mom had a problem with her sickle cell anemia this morning and she is in the hospital. It’s the one where you were born. She’s getting medicine and will be there until tomorrow.”

The doctors and nurses are taking very good care of her. We’ll go pick her up together tomorrow.”

Teenagers

Why you need to adapt your script

Teenagers can understand much more about what is happening but might feel more pressure to hold it together.

They might say they feel fine but privately feel anxious inside. Keep checking in on how they’re doing even if they say they’re okay.

Teenagers are also more autonomous so it can be a good idea to brainstorm ideas for how they can support their parent in the hospital and when they’re home.

What this looks like

You can suggest they do a self-led activity for the parent like to make a playlist, arrange flowers, bake a cake, or make them a collage of things they love about them.

Teenagers often worry about practical impacts—getting to and from school, sports and to their friends’ houses, whether they’ll be taking on any new chores, and so on—so be sure to address how all of that will work while their parent is in the hospital.

Prepare for a hospital visit ➡

Prepare for a hospital visit

If the parent will be in the hospital for longer than a few hours, the child might want to go visit them. First, make sure the parent is well enough for a visit and that their medical team says it's ok. Then choose a time and how long you will stay. One of the best times to go is during mealtimes since their parent will likely be awake and won't be undergoing any testing or getting their vitals taken while they're eating.

Before you go, follow these tips to prepare the child for the visit:

Prepare the child emotionally for the visit.

- If the parent looks different, for example, if they have swelling, bruises, a rash, or any tubes in their body, ask them to take a picture of themselves then show it to the child ahead of time so they can be prepared.
- Let the child know they might feel angry, scared, or teary and that that's ok—there's no right way to feel about a parent being in the hospital.
- Acknowledge that hospitals can be anxiety-provoking. Tell the child that, as long as they stay for a few minutes, they can leave any time. You can come up with a code word like *pineapple* they can say if they are ready to go.

Describe the room in as much detail as possible. You can include details like:

- whether the parent has a roommate
- what number floor they're on and room they're in
- what the common machinery in a hospital room does (you can look at pictures of these online together)
 - **pulse oximeter:** makes sure they have enough oxygen
 - **blood pressure cuff:** makes sure their heart is beating right
 - **electrode:** listens to their heart
 - **IV:** helps get water and medicine in their body quickly without them having to swallow it
 - **adjustable bed:** makes it easy for them to sit up to talk to doctors or watch TV or lay flat so they can sleep
 - **call button:** gets a nurse to come right away if they need anything



When you arrive at the hospital, remember to wash or sanitize everyone's hands before you go into the room. If you need to, put on a mask or gown to protect the parent from germs.

Once you're there, let the child know how they can interact with their parent. For example, they may be able to lie down and cuddle with them in the bed. Or they may need to sit in a chair next to the bed because their parent is hooked up to tubes.

Point out the machinery in the room you talked about to help the child feel more at ease.

Prepare for a hospital visit (continued)

If the parent is up for it to it, they can check in about their child’s homework, friends, sports and so on to give a sense of normalcy to the visit and establish that they are still in a parental role even when they’re in the hospital.

If you are with **young children** and they are getting wiggly and impatient, take frequent breaks. Go to the cafeteria, vending machines, visitor’s area, or gift shop.

School age children can do their homework in the hospital room or play cards or a board game with their parent if they are well enough.

Since **teenagers** want to be seen as adults, if the parent is comfortable with it, they can stay in the room for any conversations with their parent’s doctors. And If they’re old enough to drive, they can drive themselves to and from the hospital and visit their parent by themselves.

When a child’s parent is in the hospital, they need information, reassurance, and a sense that there is a plan. You don’t need to do any of the above perfectly—what matters most is that the child feels informed, supported, and loved by the adults around them.

