

Mental Health in Kids With Chronic Illness

Emotional support for children with medical conditions

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<https://childmind.org/article/mental-health-in-children-with-chronic-illness/>

When a child has a medical condition, families are, naturally, focused on finding and maintaining the most effective care. Concerned about the child's physical well-being, it's easy to overlook the emotional toll a chronic illness can take.

Whether it's a food allergy or asthma — conditions that require long-term vigilance — or a cancer diagnosis, kids may need help to handle it in the healthiest possible way. Parents, too, may need help processing a child's condition and their own feelings about it. In fact, parents are often more upset than their children, and if they are struggling it can impact their child as well.

How a medical diagnosis can impact your child

The most common issues kids with medical diagnoses face are depression and anxiety, says clinical psychologist Lauren Latella, PhD. And they can be triggered “by anything that's going to spark kids to start thinking about themselves differently, as having a limitation.”

Chronic medical illnesses can disrupt:

- **School:** A child may miss periods of school or have to be home-schooled if they are ill.
- **Friendships:** Sick kids or kids with eating or activity restrictions may feel isolated from their peers.
- **Extra-curricular activities:** A kid may not be able to participate the way they did before they received the diagnosis.
- **Social activities:** Something like a food allergy or having to take medication on a schedule can make even attending a birthday party or sleepover difficult for kids.
- **Normal emotional/psychological development:** If the illness is diagnosed at a young age and follows your child into adolescence, it can derail the normal behavioral development teens go through as they become more independent and separate from their parents.

As a result of these disruptions in their day-to-day lives, kids with medical conditions often feel left out or self-conscious. Depending on their age, these feelings can lead to behavioral issues, anxiety and depression.

Not all children will struggle, however. Some, especially younger children, may not fully understand what is wrong. If the people around them help them feel comforted and secure, they may be resilient and act like any other child. Some factors that make a child more likely to struggle are:

- Experiencing complications in treatment
- Facing threats to bodily integrity (like surgery, especially multiple surgeries)
- Being older (teenagers are more likely to worry than little kids)
- Having parents who are struggling

When parents are struggling

In some situations, children may be less affected than their parents. “Parents may have a really hard time and that can set the tone for the recovery,” notes Jamie Howard, PhD, a psychologist at the Child Mind Institute. That’s because children can pick up on when a parent is upset, and it can make them upset, too. If they’re very young, they may feel confused and anxious because they might not understand why their parent is worried. Or if a parent is feeling like their child is very fragile or in danger, the child may start thinking that, too, and it can affect their self-identity and ability to be resilient. Parents might also have a hard time setting limits, which can make kids feel anxious and start acting out.

Some parents can even develop post-traumatic stress disorder. “Parents can get in this mode where all they do is focus on their child and all the many doctors for their children and getting their children healthy,” says Dr. Howard. “And then months after it seems like things have calmed down and their child is okay, they’re not functioning because they’ve been in fight or flight mode.”

For parents who need help processing their own feelings, reaching out to a mental health professional can be an important first step to feeling secure, both for them and their child.

How parents can help

Many parents want to protect their children from the difficult and painful realities of having a medical illness. They may avoid talking about the medications or the specifics of the illness — or sometimes even the name of the illness — because they’re afraid it’s going to make the child more frightened. But, says Dr. Latella, “not talking about things at a developmentally appropriate level actually causes more worry and leads to depressive symptoms later on.” If you’re not sure how much information to share with a child, a mental health professional can help you understand what’s developmentally appropriate.

Dr. Howard recommends to always pair that description with an explanation of what you are doing to help the child get better in order to help the child feel empowered.

Guidelines for older children

When kids get to be older, they may want or need to take more control over their treatment, but they may also be less adherent. “Twelve to eighteen is the critical period of adolescence in normal development where kids are trying to get more autonomy,” Dr. Latella says. “So parents may see some oppositionality in the form of family conflict.”

The best way for parents to respond to this behavior is by involving the adolescent as much as possible in decision making and conversations, so they can feel like they have some control over their treatment. Parents should also set clear, consistent messages about what is expected of the adolescent to manage their behaviors. Dr. Latella suggests making contracts with teens about medication adherence and other aspects of managing their illness.

And then to do your best to give your child as normal a life as you possibly can. This includes continuing to set the same behavioral expectations and boundaries you would with a healthy child. If kids are medically able, they need to complete school work and continue to help around the house in the same way their healthy siblings do. It’s up to parents to make sure a child with a diagnosis doesn’t automatically get a “pass” just because of their medical condition. “Parents should be mindful of when they are becoming overprotective or too lax,” says Dr. Latella. “It is important to give any child structure; therefore, maintaining the family routine prior to the illness diagnosis is important.”

Signs that your child needs professional help

Younger kids and adolescents will most likely have different reactions to the stress brought on by a medical condition and everything that goes along with it since they understand illness in a different way as they get older.

Younger kids (between the ages of three and ten) who worry about their condition, Dr. Latella explains, are more likely to exhibit behavioral symptoms, like being oppositional and other kinds of acting out. “It’s normal to expect some of that in the beginning,” says Dr. Latella. “But if after a few weeks those behaviors still persist then that’s when it becomes more problematic.”

Warning signs to look out for in kids ages three to ten include:

- Thinking obsessively about their health
- Worrying about their parents’ or siblings’ health
- Disrupted sleep caused by worries
- Being disruptive in school
- Blaming themselves for the illness
- Avoiding any reminders of the illness such as not wanting to go to the doctor, having panic attacks or outbursts around a doctor’s appointment
- Having headaches, or stomachaches — physical symptoms that are not related to their medical condition

In adolescents, stress manifests more as depression and disruption of interpersonal relationships. Warning signs in kids ages ten to eighteen include:

- Social difficulties
- More withdrawal from and conflict with peers
- An inability to find pleasure in activities that normally brought them pleasure
- Changes in grades (that could be linked to having difficulty concentrating because of worries)
- Hopelessness

How clinicians can help your child

There is a lot that clinicians can do to mitigate the experience of having a chronic medical condition and it all starts with talking opening and honestly with your child at a level that is appropriate for their age. For younger kids, Dr. Latella says mental health clinicians may work with younger kids in the following ways:

- Reading storybooks about physical illness: Even if the actual disease that the character in the book is going through isn’t labeled by name, it’s validating for a little kid that it’s okay to be worried. These books often focus on some of the scary stuff that kids need to do to get healthy in order to normalize it and make it a little less frightening. “There’s a lot of helpful imagery in these books,” says Dr. Latella. “For example, thinking about about medicine as soldiers that are fighting off the bad cells in our bodies.”
- Practicing procedures: Going through the steps for things like blood tests on dolls helps a child know what to expect. “I wouldn’t use real needles,” says Dr. Latella, but I might say, ‘Can you help me wipe the doll’s arm where we’re going to clean the site, and can you hold onto the tube?’ So really prepping them for doctors’ visits and getting them involved so they feel some control over what’s going on.”

- Developmentally appropriate communication: Even very little kids know that something is wrong and if parents or health care providers are not communicating with them about it openly it can add to the child's confusion and fear or give them the idea that the illness is something they cannot talk about.
- Setting behavioral plans: Dr. Latella uses behavioral charts with kids that include reward systems (like sticker charts) for things like taking medication on time or keeping surgical sites clean.

For teens who are more prone to depression and anxiety than behavioral symptoms, the therapy is different. Therapy for older kids focuses on:

- Cognitive behavior therapy (or CBT): Dr. Latella places a lot of emphasis on validating the teen's feelings, acknowledging that what they are going through is not typical and not what their peers are dealing with. "I might even say, 'This situation is horrible, and you're allowed to be angry, and you're allowed to feel different, because this does make you different,'" she says.
- Psychoeducation: Teens learn about how thoughts, feelings and behaviors are interconnected, with a focus on the medical treatment. Clinicians might ask the teen to consider what are the worrying thoughts they have about the treatment? About the illness? How does it change their identity? How do these things link to their behavior?
- Family Therapy: During these sessions, which include parents, siblings and the child with the illness, the therapist encourages parents to model open communication with their children. These sessions also give siblings who can feel shut out or neglected—to talk about their feelings. It can also be a time and space for the child with the illness to explain exactly what it's like for them

**Between Families Newsletter
Training Questions
Preparing Kids for a New School Year
September 2021**

Name: _____ Date: _____

Signature: _____

**PLEASE COMPLETE THE FOLLOWING QUESTIONAIRRE FOR ½ HOUR CREDIT AND
SUBMIT TO YOUR ASSIGNED FOSTER CARE WORKER**

1. The most common issues kids with medical diagnoses face are?
 - A) ADHD
 - B) PTSD
 - C) Depression and Anxiety
 - D) Anxiety
2. (True/False) Chronic medical illnesses does not disrupt normal emotional or psychological development.
3. From the list below, which is NOT a factor that makes a child more likely to struggle?
 - A) Experiencing complications in treatment
 - B) Facing threats to bodily integrity (like surgery, especially multiple surgeries)
 - C) Not take the proper dosage of medicine.
 - D) Being older (teenagers are more likely to worry than little kids)
 - E) Having parents who are struggling
4. Some parents can develop _____.
5. How can parents help?
 - A) Cuddling and providing comfort
 - B) Empower the child by paining a description with the explanation.
 - C) Shelter the child by not telling them what the illness is.
 - D)none of the above

6. (True/False) For older children, Twelve to eighteen is the critical period of adolescence in normal development where kids are trying to get more autonomy.
7. It's up to parents to make sure a child with a diagnosis doesn't automatically get a _____ just because of their medical condition.
8. Which of the following are warning signs to look out for in kids 3-10?
- A) Disrupted sleep caused by worries
 - B) Being disruptive in school
 - C) Blaming themselves for the illness
 - D) All the above
9. In stress _____ more as depression and disruption of interpersonal relationships.
10. (True/False) There is a lot that clinicians can do to mitigate the experience of having a chronic medical condition and it all starts with talking opening and honestly with your child at a level that is appropriate for their age.

ANSWERS in Red.

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