



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

Welcome guide

Welcome.

If you're parenting while living with a chronic health condition, you're not alone.

I created this guide to help you quickly find the resources that are most relevant to your family. Whether you've just been diagnosed, have been living with your condition for years, or support families as a healthcare professional, this guide will help you know where to begin.



1) Who is the Art of Parenting While Sick for?

The resources on the website are for any parents, grandparents, and other caregivers who are managing a chronic health condition, as well as the clinicians, nurses, and foundations who support them.

By chronic condition, I mean a long-term genetic, autoimmune, infectious, or other serious health condition that:

- has lasted at least one year or more and requires ongoing medical care
- limits your daily life, including work, parenting, social activities, or household responsibilities
- causes ongoing symptoms or unpredictable flare-ups
- may worsen over time or go into remission and return
- can require emergency treatment or hospitalization
- requires ongoing medication or treatments (such as dialysis) to stay well

Common conditions ➔

Hundreds of millions of parents around the world are living with chronic health conditions. Yet most parenting books are predicated on the assumption that parents are healthy and able-bodied.

Parenting while managing a chronic condition comes with unique emotional and practical challenges like needing to explain your condition to your child, planning for hospitalizations, navigating medical emergencies, talking about heritable conditions, and coping with guilt on the days when you’re unwell and parenting from the couch.

That's why I created The Art of Parenting While Sick.

Common chronic conditions

This list is illustrative, not exhaustive, as there are more than 10,000 chronic diseases. An estimated third of these are parents.

	Condition	Number of people worldwide
1	kidney disease	800 million
2	osteoarthritis	595 million
3	diabetes	540 million
4	chronic obstructive pulmonary disease (COPD)	400 million
5	hepatitis	350 million
6	endometriosis	190 million
7	heart failure	64 million
8	epilepsy	50 million
9	human immunodeficiency virus (HIV)	40 million
10	severe asthma	38 million
11	myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS)	24 million
12	sickle cell anemia	20 million
13	cerebral palsy	17 million
14	rheumatoid arthritis	18 million
15	Crohn’s disease	10 million
16	Parkinson’s disease	10 million
17	lupus	5 million
18	scleroderma	2.5 million
19	multiple sclerosis	2 million
20	myasthenia gravis	700,000

2) What are the resources on the site? How should I use them?

On the [Resources page](#), there are several free downloadable PDFs. I add new ones regularly. There are many ways to bring these to life, for example:

- bring them to family meetings and go over the content together
- share them with your partner, family members, and close friends in your support network
- bring them to your doctor's and therapist's appointments to help you process the content and write scripts

3) What if I've just been diagnosed?

First of all, I'm sorry. It is so difficult to learn that you have a new condition. Our community is filled with parents who understand what you are going through, each in their own way.

I hope the resources on the site will help you move from grief and uncertainty to feeling like you have a plan to help your family better communicate about, cope with, and support you in navigating your new condition. You can start by developing a script using the [Talk to your child about your condition](#) and consider buying a book from the list [20 books for helping your child understand your condition](#).

The Peanut Butter & Jelly Approach

Every conversation about your health with your child should include two ingredients (just like a PB&J):

-  information
-  reassurance



If you give your child information without reassurance, for example, *"I was just diagnosed with a disease called Crohn's."* they will likely be worried about you and feel anxious.

And if you give your child reassurance only, for example, *"I am not feeling well but don't worry I'll be fine."* they will worry there is something you're not telling them.

Even if you yourself feel anxious about your condition, you can still be reassuring for your child. You can talk about the fact that thousands or millions of people have the same condition as you and take the same medications or that your doctor specializes in treating your condition. The goal of the reassurance is to let your child know the adults around them have a plan.

Blending information and reassurance looks like this: *"I was just diagnosed with Crohn's. It is a disease that makes parts of my intestines red and swollen. It can be painful. I'm probably going to have it the rest of my life. There are more than 10 million other people with Crohn's. My doctor has a treatment plan. One of the medicines she suggested is called infliximab. Millions of people around the world take it, too, and she thinks it will really help me."*

Remembering to combine these two ingredients in as many conversations as a possible is a great step to mastering the art of parenting while sick.

4) What if I am going to be hospitalized for my condition?

Four out of five hospital admissions are people with a chronic health condition and more than 500 conditions can cause medical emergencies.

The good news is that you can plan for any kind of hospitalization, whether it's planned or unplanned. You can start with these two documents [Help your family handle a hospitalization](#) and [Create a hospitalization checklist](#).

5) What if I want to get pregnant? Or what if I've developed my condition since my last pregnancy?

There are many questions you can ask during appointments leading up to and during a pregnancy to help you better manage the process. You can use the [Talk to your doctor about family planning](#) document to talk to your doctor about how your condition could impact your fertility, pregnancy, childbirth, medication use, postpartum care, and more.



Over the past several years, I've worked with hundreds of parents living with chronic health conditions. They are some of the kindest, most thoughtful, and most devoted parents I've ever met.

Parenting while managing a chronic illness isn't easy, but it is absolutely possible to raise happy, confident, and emotionally resilient children.

I hope the resources on this site help you build strong communication and coping skills in your family, prepare for the unexpected, and move from worry and uncertainty toward greater connection and confidence.