



# PARENTING WITH A CHRONIC CONDITION:

## A SURVEY OF PARENTS



2025

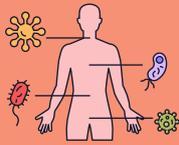
# An overview of the participants



26 parents



8 countries

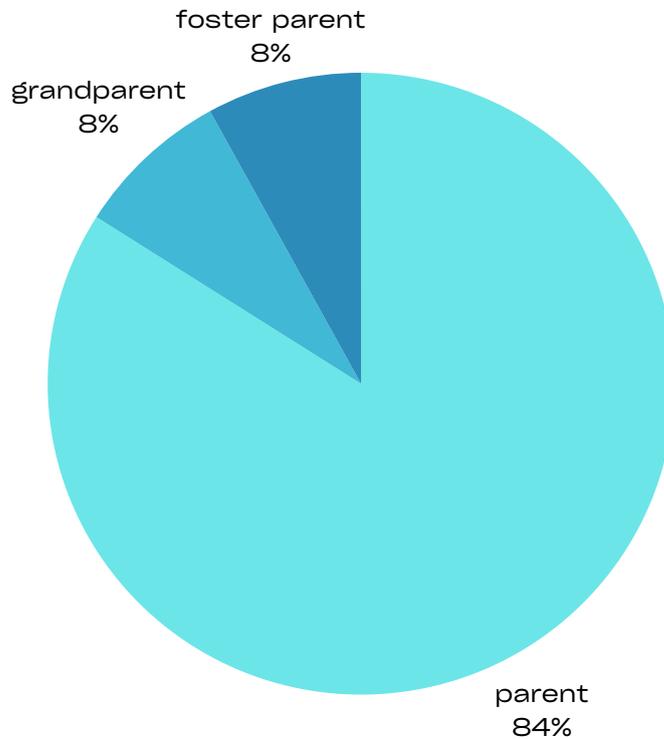


20 conditions

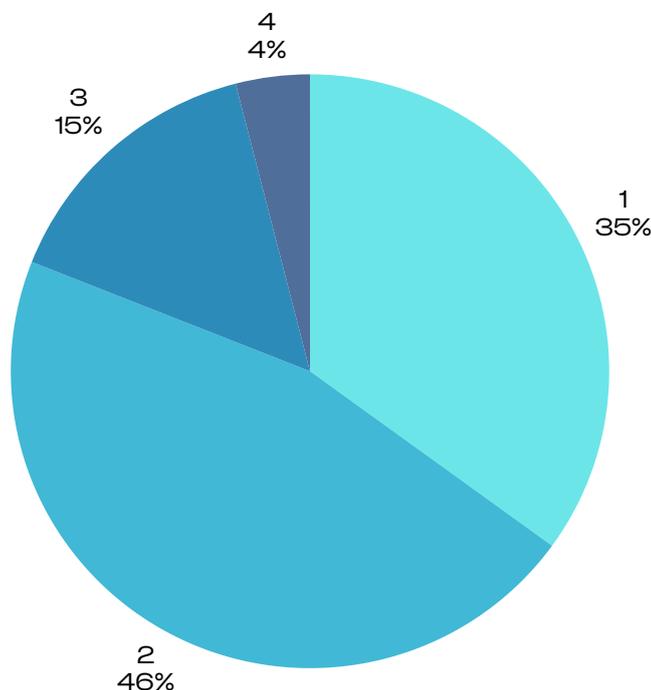
- Addison's disease / adrenal insufficiency
- amyotrophic lateral sclerosis (ALS)
- ankylosing spondylitis
- asthma
- cancer
- chronic obstructive pulmonary disease (COPD)
- Crohn's disease
- Cushing syndrome
- depression
- diabetes
- fibromyalgia
- Grave's disease
- long covid
- mast cell activation syndrome (MCAS)
- myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS)
- osteoarthritis
- postural orthostatic tachycardia syndrome (POTS)
- psoriatic arthritis
- rheumatoid arthritis
- Sjögren's syndrome

**Note: The answers in the survey have been edited for clarity and brevity.**

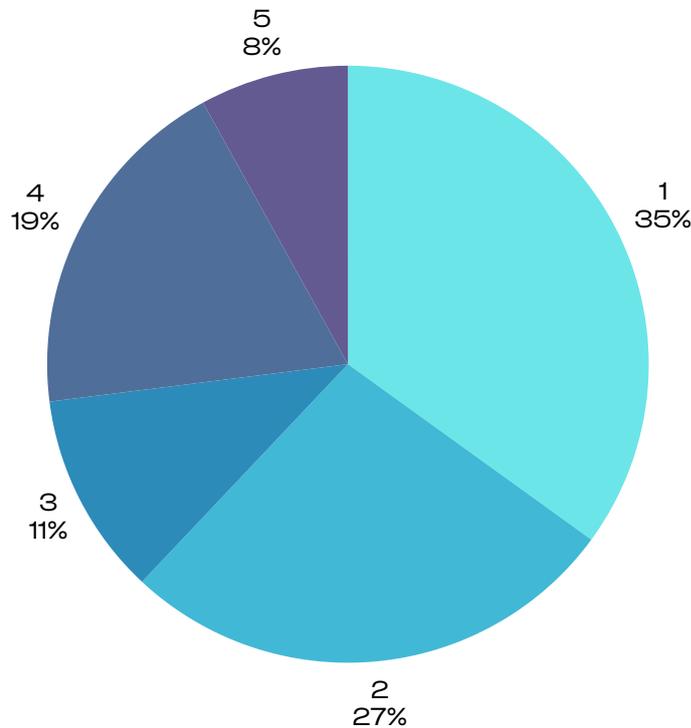
# 01: Which of these caregiver labels best applies to you?



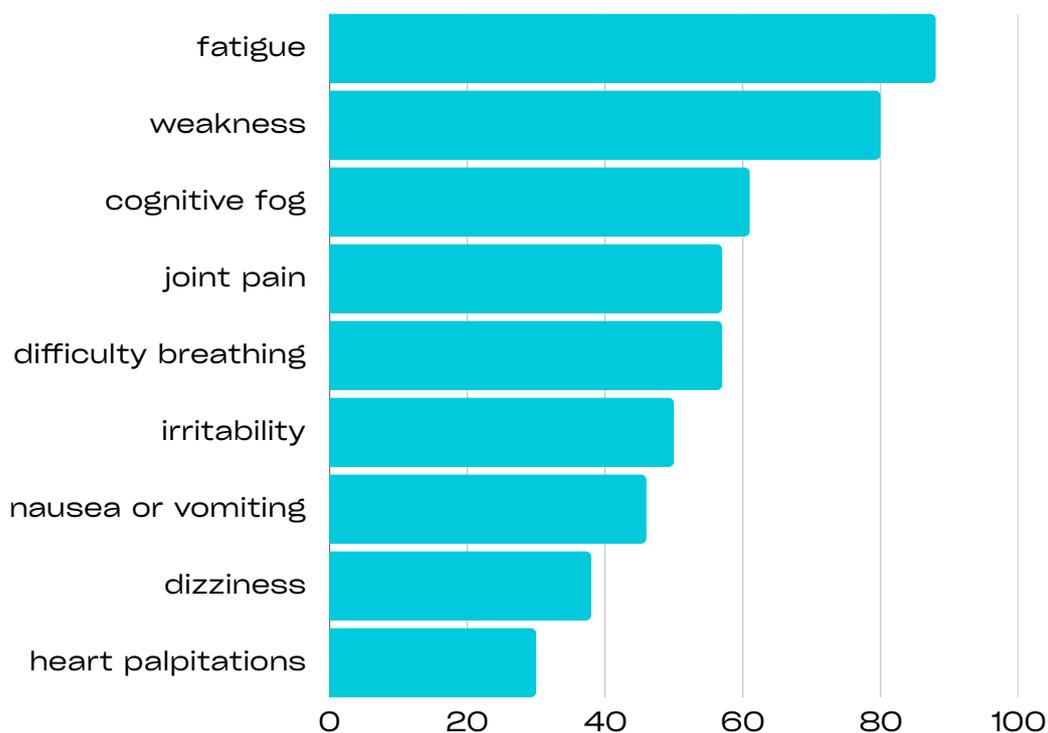
# 02: How many children do you have?



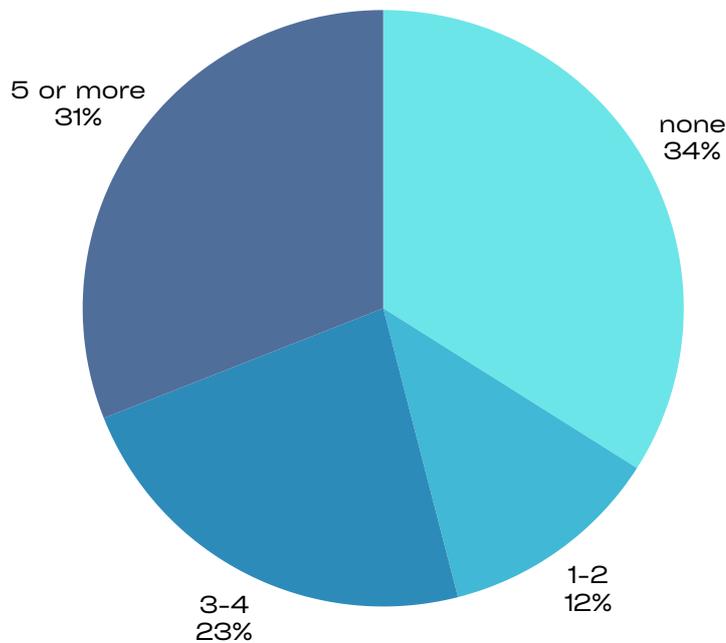
### 03: How many chronic conditions do you have?



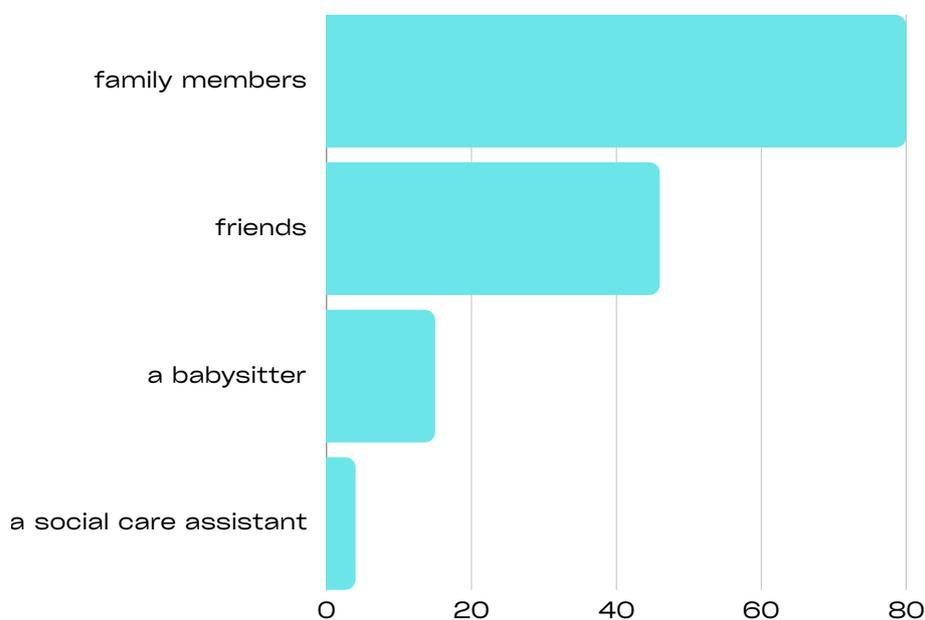
### 04: When your illness(es) flare(s), what are your symptoms?



05: How many times were you in the hospital (emergency and planned) in the past two years?



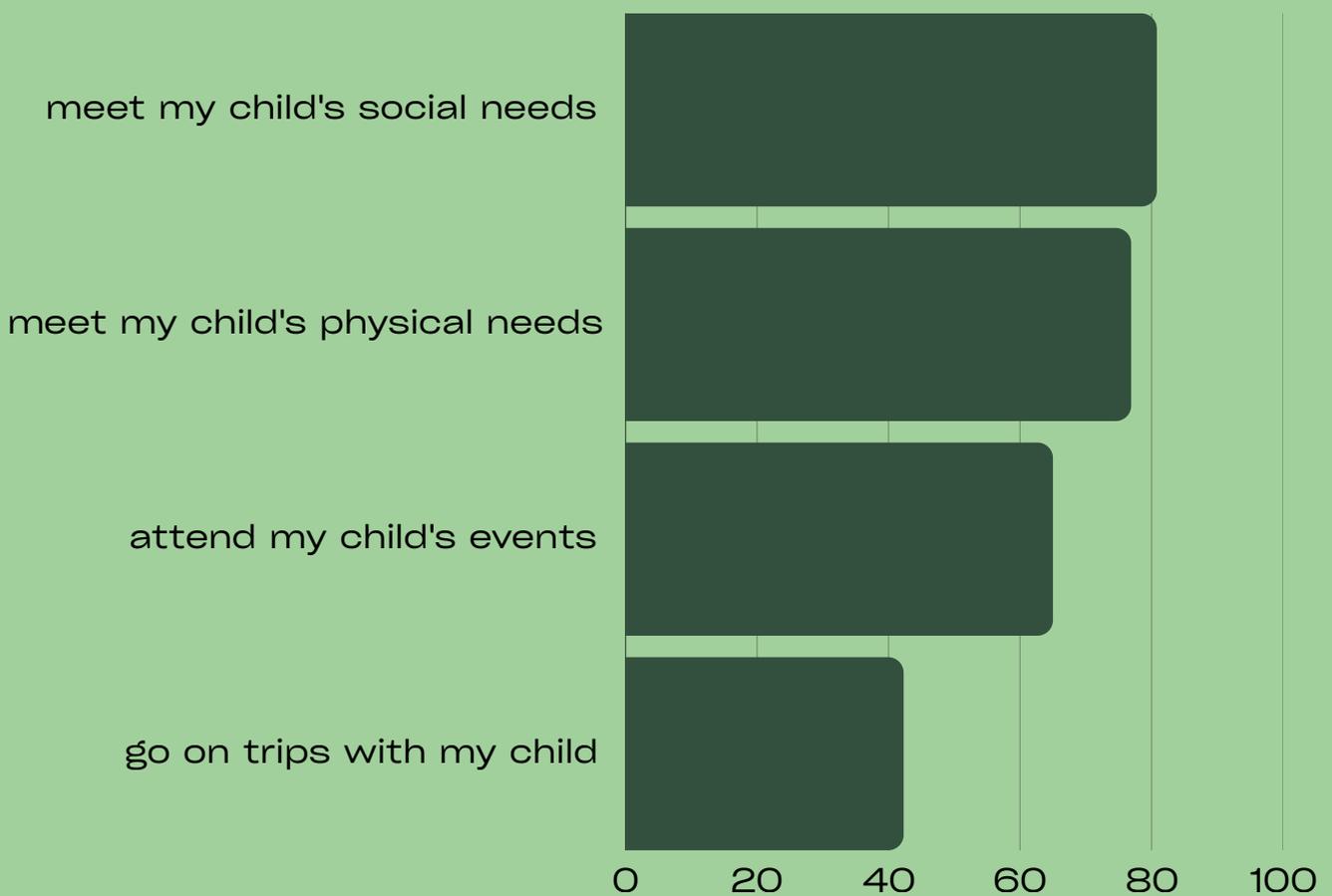
06: Who in your support network helps you when you are in a bad flare or in the hospital?



● Keeping up with children can be hard when you're not feeling well.

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● 07: Which of these is difficult for you to do on a daily basis?



● Participants also noted it can be difficult to:

- help my child with their homework
- keep up with housekeeping
- attend to my child's medical needs
- give my child ongoing psychological and mental support

## 08: What is an example of a time your child was frustrated by one of your limitations? What was the limitation and how did you handle it?

I don't always feel like I have the mental or physical energy to have their friends over. At their ages, they really enjoy that time with their friends and can't understand why that might be hard for me at times.

I was in the hospital for birthdays several times over the years. I overdid the presents through guilt and made sure other family members spoiled them.

Juice is a go-to for me if I have low blood sugar. There have been numerous times when I had to drink our only box of juice and then tell my small children they couldn't have any. Now they mostly know I \*need\* it so I don't "get sick".

My kids have just been so patient and tolerant. A lot of the time, my husband compensates, and we ensure the kids do not miss out on going out or away together. I don't join them, but he ensures that they still get to do things.

I used to coach football and basketball, but this year, I was only able to watch two games.

I'm not always on time due to this illness. My child had to serve detention when MY medical issue kept us from getting her to school on time. Late by minutes, not hours. I took her to a local arcade later to apologize for how my problem affected her.

I have missed out on many of my children's activities, but we always make sure that my husband or a grandparent is there.

I couldn't play with my child because of asthma / breathlessness. I struggled to go out in cold weather, so we missed playing in the autumn leaves and snow together.

My youngest child (autistic) has lots of energy and always wants to be on the go. He gets very upset and has outbursts and spends way more time on screens than I prefer because I can't take him and the dog for a walk, or go to the park, or ride on the light rail. I typically apologize that we can't go, acknowledge his feelings, do my best to show up, and be present in any way possible. One thing we enjoy is lying in bed and watching a movie together.

Hospital admissions were always the most disruptive for my children, especially at holiday times. I've missed many Easters and Christmas holidays, and I spent a few of our summer holiday vacations in hospitals.

My kids used to be sad I couldn't pick them up. We all cried about it.

# 09: What is hardest for you when you try to talk about your illness with your friends, family, coworkers, and others?

**73%** Most people don't realize 96% of disabilities are invisible so they think because I look and act functional, I must feel fine.

**57%** People suggest solutions that make it clear they don't understand the severity of my condition (e.g. implying that taking the right vitamins, eating a particular diet, or meditating could "fix" me).

**46%** People who are healthy and able-bodied simply can't relate to what it's like to be sick so frequently.

**30%** People suggest solutions without asking what I've tried.

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- I have experienced considerable feelings of grief over the years around missing out on activities with friends.
  - I didn't talk about my condition or tell anyone. I minimized it for the first 5-6 years.
  - I spent a long time trying to hide how sick I was.
  - People underestimate the mental toll.
  - I feel like people get bored of me being unwell or in the hospital.
  - People struggle to understand the ongoing nature of "chronic" conditions and that we need help regularly.



People assume that our family dynamic is similar to theirs; however, ours is different in that my husband plays a much bigger part in responsibilities that have traditionally been seen as feminine. For example, he has much better relationships with my son's teachers, he cooks dinner, and he changes all of our baby's diapers. A lot of women mistakenly assume that I am doing all of the work, so it can get awkward sometimes when they are complaining about their husbands, and I cannot relate.

# 10: If you belong to a support group with other people who have your condition, what are the benefits?

**83%** I get tips to manage my condition.

**83%** I enjoy talking to people who intimately understand the ins and outs of my condition.

**58%** I like being able to let off steam when I am frustrated by my symptoms or the side effects of my medications.

**54%** I like being able to vent about issues I have with the medical system, such as doctors who don't know much about my condition, expensive medicines, or issues with my health insurance.

- I like supporting others. I rarely reach out for support myself.
- I feel less alone and isolated.
- I appreciate the emotional support.

# 11: If you belong to a support group with other people who have your condition, what is challenging?

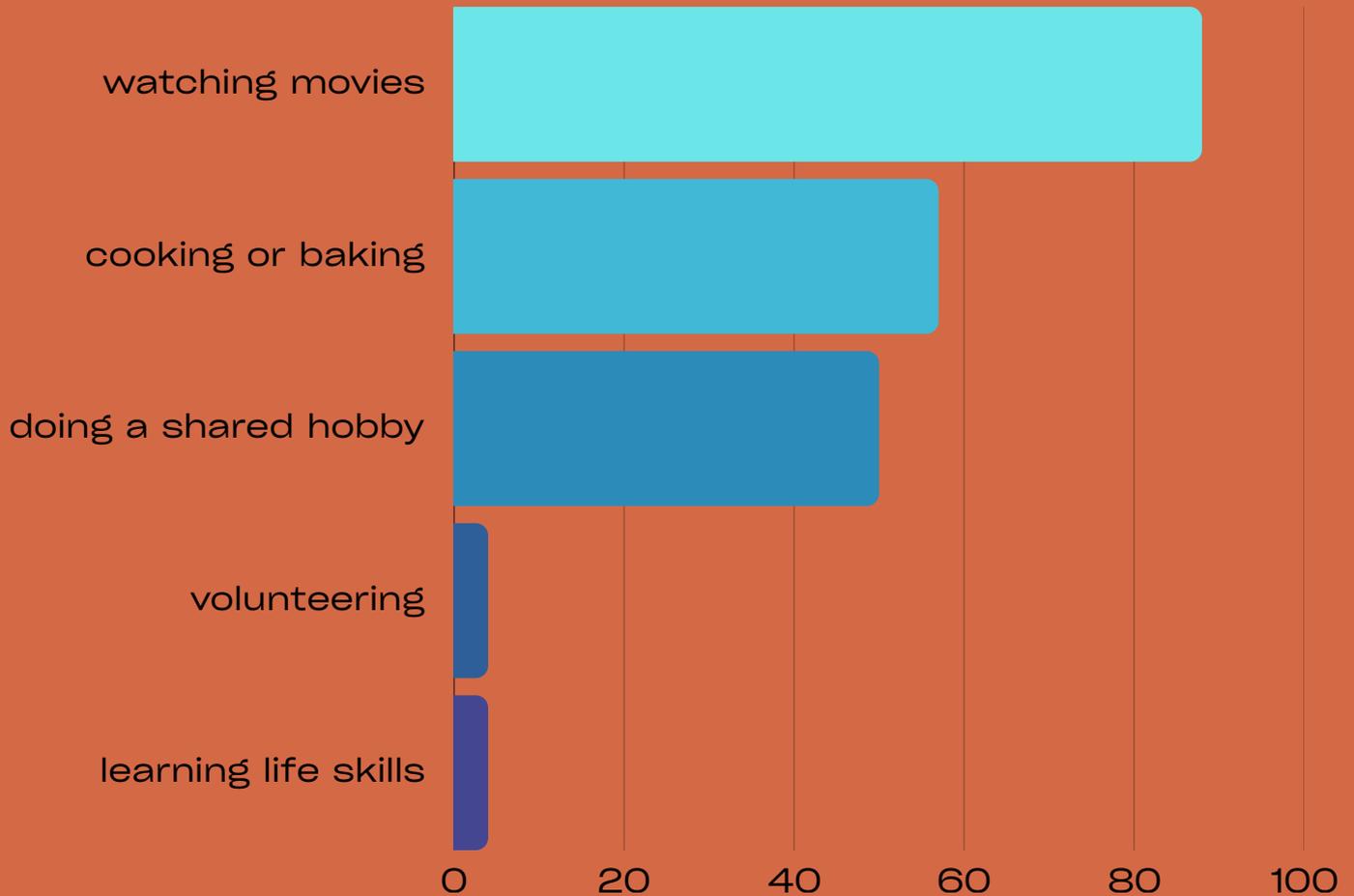
**59%** Seeing so many people struggling, since many people tend to post more when they are unwell.

**41%** Feeling like I want to help, but don't have time to keep up with all the posts.

**41%** Seeing people with my same condition who are critically ill makes me feel anxious.

- Differing views and experiences can be difficult to see and result in hard feelings.
- Feeling guilty that our diagnosis is the same, but my symptoms have progressed more slowly so I have had more time to achieve things in my life that they haven't, like having a child.
- When there are comprehensive files in a group that answer the questions they ask.
- As a healthcare worker myself (RN, LPC), the weight of how our medical system is failing so many people is crushing.

## 12: How does your family spend quality time together?



### Other answers:

- playing computer games
- playing board games
- going to see movies in the theater
- visiting beautiful places
- going on walks
- looking after our chickens



# 13: What resources about parenting, chronic illness, or parenting with a chronic illness have you found helpful?

- My training and experience as an occupational therapist, psychotherapist, and counselor.
- I find the support group Health Unlocked helpful.
- The books *This Isn't What I Ordered* and *The Invisible Kingdom*.
- None.
- Not really any, unfortunately!
- I haven't read any.
- I haven't found any.
- Very few are directly related to the illness aspect.
- I haven't found anything that addresses my lifestyle.
- Nothing.
- I haven't.
- I haven't seen any!
- Never seen any resources.

The answers to this question highlight how much of a need there is for resources for parents with chronic conditions.

# A BIG THANK YOU TO ALL THE PARENTS WHO COMPLETED THE SURVEY!



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](https://parentingwhilesick.com)