

Long COVID Transformed My Sister into a Turtle

A story about being a kid with Long COVID



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My sister is like the big boss under attack in a video game. She has all kinds of pains. It can be her head, neck, stomach, or some combination. When she hurts, I bring her an ice pack or a heating pad.





My sister is like a dark room where anything could be lurking.
She has a lot more fears and worries. I give her a big hug and tell
her I will chase all her scary thoughts away..

My sister is like a battery in a remote-control car that won't hold a charge. I really want to play with her, but sometimes her battery is too drained.



My sister is an explorer, searching for anything that will make her feel even slightly better. Improvement is the hidden treasure.



Helping Kids Navigate Long COVID: Gentle Support and Encouragement

1. Trust Their Experience

Believe them when they share how their body feels. Their symptoms may shift from day to day. Honoring their limits helps them feel heard and supported.

2. Celebrate Small Wins

Some days will be tougher than others. Progress may be hard to notice. Keep a list of little victories, such as reading a page in a book, going for a walk, or simply smiling more often. Reviewing small improvements each week is a powerful reminder of healing.

3. Discover Joy in New Ways

The activities they once loved might not feel the same right now. There are always new ways to play, create, and explore. Keep experimenting with gentle, enjoyable experiences that don't worsen symptoms. Whether it's storytelling, crafting, or simply cloud-watching.

4. Remind Them They're Not Alone

Feeling isolated is common, but they belong to a strong, supportive community. Stories of perseverance, mindfulness, and resilience can help them feel connected. Caregivers, friends, and even characters in books can offer comfort and encouragement.

What is Long COVID?

Long COVID is a post-viral illness that affects children, teens, and adults. Once you get over an initial virus such as COVID-19, you continue to remain sick with new or changing symptoms over time. It can last for months or years. Other post-viral illnesses are myalgic encephalomyelitis (ME/CFS), orthostatic intolerance, mast cell activation syndrome(MCAS), Pediatric Acute Onset Neuropsychiatric Syndrome (PANS), Fibromyalgia, and more. Many people have multiple post-viral illnesses at the same time. Long COVID causes over 200 symptoms. While symptoms may be different depending on the person's age, the most common symptoms for kids are:

- Trouble sleeping
- Waking up tired
- Daytime sleepiness/low energy
- Just not feeling good
- Phobias, or fear of specific things
- Refusing to go to school
- Itchy skin or rash
- Headache
- Heart racing (palpitations)
- Feeling lightheaded or dizzy
- Change in or loss of smell and/or taste
- Not wanting to eat, low appetite
- Feeling sad, worried, scared
- Trouble with memory or focusing
- Body aches
- Back pain or neck pain
- Stomach pain
- Nausea or vomiting

Source: www.longcovidfamilies.org

Long COVID can affect every part of the body, from the head to the toes, the brain, and the body. Each person's symptoms and severity are unique to them. No one knows how long it lasts or how to recover from it. Many people do improve with treatment and the passage of time. Recovery is different for every person.

To learn more about post-viral illness and strategies for living with an energy-limiting disability, please visit:

Long COVID Families <https://longcovidfamilies.org/>.

Long COVID Kids
<https://www.longcovidkids.org/>

Bateman Horne Center
<https://batemanhornecenter.org/>

Dysautonomia International
<https://www.dysautonomiainternational.org>

Long COVID Alliance
<https://longcovidalliance.org/>

Medical Disclaimer: The information provided here is for general knowledge and educational purposes only. It is not intended as medical advice, diagnosis, or treatment. If you or your child is experiencing health concerns related to Long COVID, please consult a qualified healthcare professional for personalized guidance. Always follow the advice of your doctor or other medical experts when managing symptoms or making health-related decisions.

About the book:

Millions of children and teens around the world have been deeply affected, physically, emotionally, and mentally, by Long COVID. They desire to be seen, understood, and included in the world around them.

Through playful descriptions and whimsical illustrations, this book helps young readers understand what it's like to live with long COVID while offering supportive ideas for ways to help. It also reminds kids and parents alike that they are not alone in this journey.



COPYWRITE 2025
978-1-950535-16-3
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DOTTIE LONI PUBLISHING