THE CATALYST

How to support a loved one with chronic illness

Many face a lack of understanding from family and friends. "You don't look sick" is something they are getting used to hearing. Or people tell them, "I feel tired at the end of the day, too." For Sarah, it's a lot worse than feeling tired – more like being hit by a freight train - but it's too exhausting to keep educating people about her condition. It's disheartening to have to keep fighting to be seen, believed, and understood. Like many others living with chronic illness, Sarah ends up feeling like she has to stay silent to make people feel comfortable.

By: Nicole Chevrier | Posted: June 8, 2023

Sarah is 32 years old and has two young children. She used to be a primary school teacher. Sarah loves kayaking, hiking, and running. She ran her first marathon two years after her first child was born. But she doesn't do that anymore – not since she developed Long COVID, also known as Post-COVID condition, due to a COVID infection two years ago.

There are many things that Sarah doesn't do anymore. She has stopped working, exercising, cooking, walking the dog, and driving. Sarah has to rely on her husband for everything. She is too ill to take care of or play with her children, and this makes her feel guilty. Most days, she has trouble getting out of bed or talking for too long. She is battling a laundry list of symptoms like dizziness, tachycardia, heart palpitations, headaches, and difficulty breathing. She spends most of her time lying down in a darkened room because too much light and noise makes her brain hurt. "I never knew it was possible to feel this sick," she says.

Your life is cancelled until further notice

The experts call it functional impairment. People like Sarah would call it "your life as you know it is over." You might find it surprising that a young, healthy person could be incapacitated by an illness like Long COVID. After all, a widespread misconception is that this illness only affects older people or those with underlying health conditions. Hundreds of thousands of cases are proving otherwise.

Sarah is now part of a growing group of people in Canada who are living with an invisible illness. You may not realize it, but you probably know at least one person who lives with some form of a chronic illness or disability. It's understandable in a way – who wants to broadcast their health problems to the world? Many suffer in silence at home, invisible and ignored. But unlike some people who have well-documented, diagnosed conditions, people living with Long COVID are struggling to have their illness recognized, let alone treated. Many of them have faced gaslighting by medical professionals, who dismissed their experience, which led to long delays in diagnosis. A growing number of them are fighting to have their condition recognized by workplaces and insurance companies.

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Don’t go to an empty well for water

The world is not kind to people with disabilities. In an ableist society like ours, a person’s worth is defined by their productivity and abilities. We worship youth, beauty, and health, and any talk of illness is uncomfortable, so it’s avoided. So many people are uncomfortable with grief and feel they don’t have the skills to cope. They feel anxious seeing someone in pain, and because they can’t fix it, they feel helpless and awkward. So, cracks appear in relationships, distancing creeps in, the phone stops ringing, and friends quietly withdraw without a word.

Caution – toxic positivity ahead

Despite good intentions, we often resort to toxic positivity. We tend to act as if only positive feelings are acceptable, so we tell people who are dealing with immense loss and grief to just be grateful they’re alive and to look on the bright side. Good vibes only! Just think positive, or don’t worry, be happy. People sometimes think that resilience means ignoring the bad things, but we shouldn’t be turning a blind eye to what people are going through. Sarah often feels that people want her to pretend to be okay instead of just being there with her, not to fix anything but to just acknowledge where she is.

Some people truly don’t have the capacity to be supportive. But some people can show up and walk beside those who are going through a crisis. We can acknowledge the emotional experiences of those we care about. It is one of the most helpful things we can do for others.

A few tips for providing positive support without being toxic:

Estimated reading time: 5 minutes

1. Be authentic in your interactions. Encourage others to express their feelings and thoughts and to seek help if they need it. Avoid telling them to “look on the bright side.”
2. Be accepting and non-judgmental of others’ feelings and experiences rather than minimizing or dismissing them. Avoid trying to fix or change their feelings. Listen to them and offer support and understanding.
3. Be aware of *your* emotional well-being and seek professional support if needed. Avoid pushing yourself or others to be positive and recognize that it’s acceptable to have negative emotions sometimes.

Knowing how to empathize with someone in tough times is one of our most important social skills. Honing your ability to connect with others authentically will not only benefit them, but it will make your relationships better.

Author: Nicole Chevrier

An avid writer and photographer. A first-time author, she recently published her first children's book to help children who are experiencing bullying. When she isn't at her desk, Nicole loves to spend her time doing yoga and meditation, ballroom dancing, hiking, and celebrating nature with photography. She is a collector of sunset moments.

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