THE CATALYST

The power of connection Living well with chronic illness

Living with chronic illness means navigating daily pain, emotional challenges, and invisible struggles. Support, understanding, and access to proper healthcare make all the difference. You don't need to share a diagnosis to be an ally—just be willing to listen and care.

By: Angela Psimenatos | Posted: January 26, 2023

I was born with hydrocephalus and spastic cerebral palsy, permanent neurological disabilities that affect information processing speed, coordination, speech, balance, and walking ability. I have chronic pain from increased muscle tone. I consider myself fortunate as I can walk and have achieved some significant milestones. In 2011, I acquired chronic facial pain following a viral infection. While the infection resolved itself, the pain persisted, and I developed generalized chronic nerve pain.

Understandably, this affected my mental health: I became withdrawn and depressed. Living with an invisible illness can be incredibly isolating, so finding appropriate supports is crucial. Pain management is important, but so is social connection—finding people who understand the mental health impacts of having an invisible illness. A person doesn't have to have a disability or the same diagnosis to be a supportive friend and ally. Here are some facts about living with a chronic illness and its effects on mental health.

1. **Chronic illness is often invisible, but it presents real, daily challenges**

People with chronic illness may be employed, have a full family and social life, but this comes at a great physical and emotional cost. Often after volunteering or socializing, I need to rest for extended periods of time. Believe them when they say they are tired and allow them to rest. Someone may be cheerful yet depressed, anxious, or in physical pain. In this sense it is like smiling depression: just because someone may be smiling, it does not mean they are not in pain.

- **Chronic illness varies from one day to the next**

Chronic illness doesn't go away, but it varies from day to day and is affected by sleep quality, and pain triggers (noise, weather, time of day, etc.). Some days are better than others. Even close people may not be able to tell how the person with chronic illness is feeling. Asking goes a long way.

- **Our illness is one aspect of our lived experience**

It's important to focus on things we enjoy, like being with people who see our whole selves beyond our illness. This gives us energy, boosts our mood, and reminds us that we are valued as we are. This can come from support groups, friends, family, or colleagues. People who acknowledge how hard it is to live with chronic conditions and who are willing to accommodate

us.

4. **We need to mourn the person we were before chronic illness**

Our lives may look much different from what we wanted them to be. It's normal to grieve this change, but we may need to set new, realistic goals. It's useful to have someone encourage us and listen to our struggles without judgement.

5. **People with chronic illness can thrive if we have healthcare access that is attuned to our needs**

Advocacy is crucial. If the Covid-19 pandemic has taught us anything, it's that anyone can become ill and therefore, accessing healthcare and mental health support is an essential part of living well. Oftentimes, doctors will treat the physical issue, which is important, but isn't a wholistic approach to care, since physical illness and mental health are interconnected. It is overwhelming and exhausting to try to find a a psychologist outside a hospital setting who is well-versed in the psychological impacts of having chronic illness. And the process for accessing healthcare needs to be streamlined and mental health care access should be covered by provincial health insurance plans because mental health is part of health care.

Learn more about the impact of concurrent physical and mental health conditions and ways to support those living with concurrent physical chronic illness and mental health problems or illnesses.

Author: Angela Psimenatos

A peer support worker at the Sexual Assault Support Centre of Ottawa. She loves literature and is a graduate of the translation program at the University of Ottawa. Angela is a person with a disability who also has lived experience of invisible illness and is passionate about mental health and social justice. In her spare time, she enjoys reading, writing book reviews, and doing yoga.

Mental Health Commission of Canada
https://mentalhealthcommission.ca/
350 Albert Street, Suite 1210 Ottawa ON K1R 1A4
Tel: 613.683.3755 | Fax: 613.798.2989
mhccinfo@mentalhealthcommission.ca