WHAT YOUR PATIENT IS THINKING

Learning to live in a body at war with itself

Presha Kardile explains how health professionals could have better helped her prepare for life ahead after a diagnosis of lupus

Presha Kardile

I started having symptoms in my early 20s that were initially dismissed as irritable bowel syndrome. My health worsened over the course of a year, with hair loss, severe fatigue, and joint pain adding to an ever increasing list of strange symptoms. As a last resort I had several antibody tests which eventually led to a diagnosis of systemic lupus erythematosus ("lupus"). This brought with it a sense of relief after years of misdiagnoses, but also filled me with dread about the future in equal measure.

After starting treatment, I focused on beating the disease so I could get back to normal. It took a while for me to realise that this approach did not make sense, as there was nothing external attacking my body. By trying to beat my condition, I was fighting against my own overactive immune system. This helped me accept my diagnosis and focus on moving forward.

Learning to adjust

I experienced a profound grief while letting go of the life I had lived. I tried to find the courage to face the tsunami of changes to come. These included learning to adjust to new medications that would leave me immunocompromised, and living in social isolation with an increased dependency on my care giver. These unwelcome changes deeply affected my mental health.

Support for my mental health was, and still is, crucial in ensuring a smoother transition to my new normal. A psychologist helped me manage my fear of taking the hoard of medications that I was suddenly expected to take every day. They helped me cope with the devastating realisation, as a young person, that I would potentially need to be on medication for the rest of my life.

Finding support

Daily mindfulness practices help me manage my pain. These practices are tailored to the needs of people who experience chronic pain, and they are practically achievable, considering that the intensity of the pain varies each day and can manifest itself in different parts of the body. I found a support group for people with chronic pain, which focused on acknowledging pain and the suffering that comes with it, rather than trying to put a positive spin on it. This helped me cope with my isolation and added to my existing support network. I also attended several online alternative therapy workshops that used art, dance, movement, and music as forms of expression. These introduced me to practices and resources that used my existing hobbies to help me cope with my new reality and support my mental wellbeing.

It took an incredible amount of research to find these groups and the courage to take the first step to seek help. It would have helped if, early on in my diagnosis, my healthcare professionals had shared the types of mental health support available. Being given a list of vetted resources would have helped me and my care givers navigate the uncertainty without the additional pressure of finding groups and individuals I could trust.

What you need to know

- Coming to terms with the diagnosis of a chronic illness and learning to live with it are ongoing processes that can bring relief as well as dread
- One-to-one counselling, support groups, and alternative therapies can help patients adjust to their new normal
- Having mental health support, where both patients and their caregivers can voice concerns and address misconceptions, is important in helping accept the changes brought on by a chronic illness diagnosis

Education into practice

- How could you ensure that your patients feel supported during diagnosis of a chronic illness?
- How might you incorporate an ongoing conversation about mental wellbeing into long term management of a condition?
- How can you inform and educate your patients on the types of mental health support available during a new diagnosis?

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