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WHAT YOUR PATIENT IS THINKING

“Just stay at home” was lonely and terrifying

Lisa Jensen describes how covid-19 has affected her and how important empathy is as she faces the long term effects.

Lisa Jensen

I became sick with covid-19 on 7 March. I was told to stay at home unless I thought I was dying. Those words might seem straightforward, but following them proved to be terrifying, lonely, and confusing.

Feeling like a check box

I was left on my own to manage shortness of breath, chest pain, fever, intermittently low oxygen, tachycardia, dizziness, brain fog, headache, sore throat, rash, back pain, and a myriad of other symptoms.

My doctor's only efforts to reach out came in the form of two identical emails, stating that they hoped my symptoms were “continuing to improve,” despite me letting them know that I was only getting worse. I felt like a box to check off. Not like a person grappling with an unknown and potentially serious illness. I called my doctor several times during the worst weeks. The conversations always ended in the same place: “There is nothing we can do for you. Just stay home.” It wasn't the lack of treatment options or information that troubled me most in these conversations. It was the lack of empathy. I never felt heard.

Finding others

I started to research my symptoms and read everything I could find on potentially relevant conditions. I also kept a detailed log, tracking more than 30 symptoms I was experiencing and just as many potential triggers. The most useful support and information came from a covid-19 support group. I spent countless hours comparing my symptoms and triggers with those experienced by other members of the group. We still compare notes on how best to manage ongoing symptoms. Based on this shared learning, I have made many lifestyle adjustments that have helped me tremendously.

Most people in the support group have also experienced some degree of doubt or dismissal from doctors. This can be especially difficult for those of us who never received a positive nasal swab because we either were tested too late or were never tested at all. This is notably common among those of us who got sick early in the pandemic. Believing and acknowledging symptoms is important even without that positive test result.

The importance of empathy

It is widely acknowledged that physical health is worsened by isolation and anxiety. Empathic acknowledgment of symptoms is imperative when

there are still so many unknowns. A doctor's empathy may not cure covid-19, but *lack* of empathy can cause genuine harm.

Six months have passed, and I am still not fully recovered. I let my doctor know that I am still struggling, but I haven't heard back. I understand that this is a new disease and therefore my doctors might not have the answers, but I still wish I felt heard. For now, I have given up on turning to my doctor for help and am opting not to seek more appointments with specialists. Instead, I'm sitting back and learning from the experiences of others in my support group. Having the support of this group makes the uncertainty—and my ongoing symptoms—more manageable.

What you need to know

- Showing you care, by listening attentively, expressing empathy, and periodically checking is even more important when there are so many unknowns
- Stay open and curious to symptoms of covid-19. You can learn from patients with this new illness
- Finding support from others going through the same experience is invaluable

Education in practice

- How can you support someone with the long-term effects of covid-19?
- When could you contact someone who has had covid-19 to check in on them?
- What advice can you give a patient recovering from covid-19 while we learn about the long-term effects?

Additional information for doctors and patients

- Covid-19 support group <https://www.wearebody-politic.com/covid19>.
- Newsletter for Covid-19 long haulers [-lisajensen.substack.com](mailto:lisajensen.substack.com)

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