

Please believe us - a call for empathy for Long Covid patients – Elizabeth Turp

Along with many others in the chronic illness community, I have known that there would be a post-viral health crisis from Covid-19 from the start of the pandemic. There is strong precedent: six months post-infection with Ebola, 90% of surviving patients hadn't fully recovered and 87% of those who had SARS still had health problems. There is also a history of people with seriously debilitating ill health not being believed and told, as is happening right now, that their extreme fatigue, brain fog, strange bodily pain, sleep problems, even taste and sight loss etc, are due to anxiety.

It was one of those horrific things you wish you didn't know and I have felt like a bystander watching a natural disaster, unable to do anything to stop it. What I can do is share my knowledge around coping with @22 and speak up about how people with continued ill health months after COVID-19 infections are being treated. It is all too familiar to me, both as a patient and as a therapist who frequently works with people who have had their health problems dismissed, told their pain is in their heads, some disbelieved by loved ones and those who have even later died because a doctor didn't take their symptoms seriously.

I have a complex health history myself, suffice to say it took 24 years to have endometriosis investigated and diagnosed and that I literally wrote the @21 on what it is like to live with chronic fatigue syndrome/ME. For those who don't know, even at the level classed 'moderate' it can be a living death of unimaginable fatigue, pain, cognitive problems and severe restriction. One that almost no one else understands.

A large part of the emotional toll of having complex physical health problems is having a medical culture whose response to something they don't understand can be to deny that it exists. Chronic illness patients are all too often met with the arrogance of medics who would sooner label you 'anxious' than admit they don't know what is wrong with you. There are of course many fantastic doctors out there, and two of the best I have encountered have at times told me that they don't know what to do to help me, leading to a collaborative search for information and search for coping strategies. The feeling of being believed, supported and cared for was precious.

There is of course a psychological element to living and coping with any of the physical conditions referred to here, just as with the more readily understood experience of a diagnosis of cancer: you feel fear, loss, isolation and low mood at the suffering and uncertainty. That does not mean that the illness is in your mind, the part that medicine often fails to understand is that the brain and body are inextricably linked and that stress can exacerbate pain, that trauma can show in the body but that doesn't mean there are not lesions, disease, dysfunctions that are causing real physical symptoms and need attention. Ironically, the long-term effect of not being believed and supported can of course be anxiety and depression and physical deterioration as it becomes harder to engage in positive self-care strategies.

Compassion and understanding are what is required, whether or not a medical professional knows the facts. I have experienced both being told that my pain 'isn't anything to worry about' and being left to endure it, and being heard by a doctor who vows to do what they can to help. There is a world of difference in these encounters and yes, they do affect a patient's mental state. The former decreases mood, derails hope and even damages self-image: I have even met people who have been so consistently disbelieved that they doubt their own physical reality.

My effectiveness as a psychotherapist is largely in the power of the human relationship a person experiences when they are heard, believed and fully accepted. An experience some have never received from another, whether they were abused as a child, are experiencing relational problems or live with chronic physical illness. In every encounter I have the power to assist in the healing process or do further damage, the difference between this and the doctors I speak of is that I am acutely aware of that power and aim to approach every encounter with curiosity, love and faith that the person in front of me knows their own truth. And I can sit with the discomfort of not knowing.

People experiencing longer term symptoms following COVID-19 aren't experiencing something new when they are dismissed as merely anxious - their all too close cousins are people with ME who are still fighting for adequate research and treatment after decades of dismissal with cognitive behavioural therapy (CBT). There is a frightening amount of overlap between reported symptoms in post-Covid illness and ME, all the additional symptoms patients are reporting are familiar to me. That is not to say that ME and 'Long Covid' are the same thing, they can't be, and many other conditions have overlapping symptoms: fibromyalgia, chronic Lyme disease, etc, but what we do know is that 80% of people with ME developed it after a viral infection and the protracted recovery and cycles of immune and other systemic bodily dysfunction are strikingly similar.

The only voices that make sense in this field are people working quietly on multidisciplinary approaches to recovery from multi-system illness combining deep rest, nutrition, meditation, neuroscience and psychology to reset the body's systems. There are some convincing theories on what occurs in the human brain when a person develops a chronic condition but they don't involve drug treatments, so funding for trials necessary for mainstream recognition are hard to get. But COVID-19 patients aren't there yet, they have potential lung and heart damage that needs attention, even those who haven't been hospitalized have often experienced the trauma of facing death. They have immediate need for medical care, in all senses of the word. Part of the problem of course is the invisibility of the majority of symptoms and that self-reporting of pain and fatigue is required as they cannot be objectively measured. We just need to believe people.

If an estimated 1/10 patients have post-Covid illness, many of those will get better in time. If even a small proportion of those never fully recover, we are looking at potentially tens of thousands of people

with new chronic illness in the UK alone. It is time to take a look at our culture, the way we respond to chronic invisible illness and disability with fear and avoidance, the way we don't value those who are not economically active, the lack of compassion we have for what we don't understand. Doctors, scientists, politicians, policy makers, employers, everyone, please don't wait until you experience this for yourselves before you believe all of us.