

Surviving A Pandemic – A Perspective from the Chronically Ill

An Opinion Piece & Excerpt by SJV

One reality about those who are chronically ill, is that some of us have learned to remain calm no matter how stressful the circumstances are around us as a protective measure to our already stressed bodies. Our minds are usually calm because we have done hours of meditation and deep breathing in hopes that will help heal our bodies. Either that, or we are just numb to any additional stressors because we have been through traumas of our own that don't quite compare to everyday problems. Our bodies, on the other hand, are in "flight or fight response", constantly fighting the illness or pain, even though our minds have accepted this "new normal". This new normal would be our everyday symptoms lingering and being carried around no matter what we do or don't do. Our worlds are smaller because we have no other choice, and any socializing is a treat that usually makes our spirits happy, but our bodies will probably have to recover from the next day. And then that in turn can negatively affect our minds and can take us to a sad place because all we wanted to do was feel "normal" and forget the illness, even if it was just for a couple of hours. And when our minds get sad, our immune systems aren't as strong, and our symptoms can certainly worsen; it becomes a vicious cycle.

Fast forward to 2020 when the whole world is affected by an insidious virus called COVID19 and we can't help but have a "fight or flight" response. This is certainly not on the list of a typical "everyday" type of problem. Currently, hundreds of thousands of people have become acutely ill and tens of thousands are dying from this novel corona virus. The coping measures that the chronically ill and their loved ones have been taking for years - such as grocery shopping on line or when the supermarkets aren't busy, using delivery services for necessities, diligently washing hands, no longer going to hair or nail salons, depending on a healthier person to provide any help, and of course social distancing - are all practices now being shared with the rest of the world. In other words, this is all very familiar to the chronically ill population besides the added component of now not being a minority in some of our experiences. And of course, worrying about our healthy loved ones more than usual. But trust me when I say, even in my most bitter moments in this, I have never wished for anyone else to "join this club".

Dr. Anthony Fauci, the director of the National Institute of Allergy and Infectious Diseases, who is one the leading and forthcoming experts of the reality of what is going on with this virus, validates that there is no medication YET that has been confirmed to cure or prevent this illness. There are promising trials in progress and those processes, that usually take longer periods of time, are moving fast and are already at an advanced stage due to previous studies. This translates to there being headway, but there is no set

protocol as to which drug is going to prevent or cure the majority of people that have been infected. So far there is only anecdotal evidence that it could work. (www.cnn.com/2020/03/28/health/coronavirus-hydroxychloroquine-trial/index.html)

My husband and I heard Dr. Fauci say these very words the other day during an interview, and we sort of looked at each other and sighed, as this is such a familiar conversation that we had heard many times from the health care practitioners we have seen regarding my illness. And we sort of felt like it wasn't new, that this has been our life the past few years trying different medications or treatments, knowing that it was only proven in vitro, as an example, and there was only a certain percentage of success. But we would try anyway after retaining good information and consultation, weighing the pros and cons, because that's what we felt we had to do. Sick or healthy, we need that hope that things can get better. And for those of you that may be feeling hopeless or scared about corona, those of you that may have gotten sick from it or even worse lost a loved one, I am sending my heartfelt condolences and virtual hugs to you. The way we have managed fear about illness or the heartache from a doctor or treatment that didn't help us, is just knowing that every day research is done, and we really do have brilliant scientific minds coupled with faith working hard on this. Every few seconds, a new health statistic is calculated due to live results. By the time this write up is posted, there may be more confidence about a cure! When you have taken a break from the news, and decide to tune back in again, you may learn something different and wonderful that has happened. Just because it didn't happen today, doesn't mean it can't happen tomorrow. And that mindset is what has really kept us sane.

Another useful lesson that we should all be educated about at this moment is understanding the acute symptoms of COVID19 verses allergies or some other innocuous virus. Our vitals are usually a great indicator of how we are doing, our body temperature, blood pressure, heart rate, and oxygen level. Also in terms of the corona virus, having difficulty breathing along with fever and/or digestion issues have been flagged as telling symptoms. It is also important to know when you need to simply quarantine yourself or get medical help in a hospital (<https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>). Those of us that have chronic symptoms from other health issues have learned to understand and act on the difference between acute symptoms and chronic symptoms even before COVID19. The acute symptoms are what would flag us to seek immediate medical attention (usually as indicated by our vitals). The chronic ones would be what we would add to our list of what we would discuss during our next appointment with our doctors. During this challenging time, it has become even more compulsory to distinguish acute verses chronic, and that is a discussion you

would need to have with your physician before deciding to go into an Emergency Room.

In the meantime, perhaps you can take some humble advice from someone who has been socially distancing for years. Establish a new routine to keep you busy at home, even if you aren't accomplishing a lot during your day like you used to. Socialize with family/friends through video chat or Zoom and give them the compliment of your full attention. When you feel anxious, try to visualize happier moments or future thoughts about what you will be doing at the end of this pandemic. What do you see yourself not taking for granted anymore? Meditate and practice self-love, and don't beat yourself up about how you are not being as productive as you usually are. Think of yourself as being safe at home rather than stuck at home. If possible, do something good for someone else, via the internet. Acts of kindness can really help you get out of a dark place. Create or make something with your kids whether it's art, music, or cooking. Invite sunlight into the house by opening all shades and curtains and put your favorite tunes on and dance, if you are physically able. And if the weather permits, go for a walk outside and enjoy the fresh air while physically distancing yourself from others. If you have a break down and cry, on your own or in front of a loved one, remember this is not you portraying weakness. It is you being "real" and strong enough to embrace how you are feeling. Usually when you let that "out", that little release may help you feel better. Please always keep in mind, change happens every day and even after people go through trauma or illness and feel stuck, things have a way of working themselves out. And that is my hope and vision for the current situation that we are all in, please join me in believing that this will get better.

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