

## **“Being” Chronically Ill in Today’s Society**

*An Opinion Piece & Excerpt by SJV*

“I’m having a human moment”. A somewhat modern expression in society today that is used to playfully apologize for an error of some degree. An excuse that others will recognize meaning that you had to take a moment out of your superhero life to be merely human, and that *must* have been when your mistake was made. A saying in hope that will justify your mistake, because after all you are “only human”, as the Jonas Brothers song goes! That just goes to show how society is expecting us to be successful and that would entail not being human but rather a superhuman of some sort most of the time. Being a superhuman would be measured by how much you are doing rather than what you are simply being. What are you accomplishing, can it be measured? How big is your social media presence? How much attention do you get from others? But we seem to have forgotten that we are human beings, not human doings.

Never did I become more of a “human being” after I fell ill six years ago. Eight months after our beautiful wedding, my husband and I were settled in our little apartment in Boston. I had started a new job downtown as a Senior Financial Analyst and had taken up subbing some Zumba classes in our local YMCA. Yes, I was a pretty active “human doing”. It was a Sunday afternoon and I was working on some dance routines in the studio of the Y, thinking how lucky I was, to have a loving husband, a solid job, and a side job doing something I was passionate about. As I let the rhythm of a beautiful Enrique song take over the room, creating choreography that I was excited to share with my new class; I had no idea that would be the last time I would be able to move like that.

Fast forward to six years later, after multiple debatable diagnoses, and many different but informed treatments later (western and eastern medicine), I became quite home bound and had to be OK with being “only human”. My world became a lot “smaller” and any tasks I could accomplish had to be measured by “spoonful” each day. The chronically ill community have a term called “spoonie” because that’s what you have to do, is carefully measure how much energy you use each day before you use too much, run out of fuel, and worsen your already tough situation and symptoms. I had to get to the point of congratulating myself if I just got through the day and accomplished just the basics, such as looking after myself and husband with the bare necessities. Cooking and cleaning were luxuries and holding a coherent conversation with a family member or friend was quite a feat, as opposed to the marathon of accomplishments I used to fit into my day. My perfectionist nature had to be put on a long-term hold, and I needed to be accepting about being perfectly imperfect.

Our social life became non-existent, I lost touch with many friends and family members because I couldn't make all events we were invited to. Any social interactions I had were few and far in between, and that sometimes led to overanalyzing the few conversations I did have. This, in itself, wasn't "healthy" as I began feeling defensive about many things that were said from a place of love. And I realized, even if things weren't said from a place of love and were unfair judgments made by others towards me, I told myself to let it go and not use up the energy required to justify what I was going through. I just focused any energy on the people that did "get it", and the other conversations I just kept short and general. I learned to stop comparing myself to others, or to my life before I got ill. There were pluses and minuses about social media, because it was still a way for me to have access to what was going on in the "outside world" while not being a part of it, but at the same time, we know that it isn't always a realistic representation of what people are actually going through.

I also learned what compassion really looks and feels like. I used to think I was fairly understanding of what others were going through in general, but I learned that it was more sympathy rather than empathy that I was feeling. An example of the difference would be sympathetic people may call or text, knowing you are ill, and say "let me know if I can help with anything". An empathetic person would say "Hey I'm at the supermarket", or "I have the day off, would you like to send me a grocery list" or "can I stop by and keep you company"? Don't get me wrong, both are helpful and appreciated, but I always found the empathetic folks were the ones I would lean towards accepting help from.

Some of the toughest phrases to hear when you are chronically ill is that "you need to be more positive" or "you need to pray more". Someone that tries to find reasoning or blame as to why you are not getting better rather than just being there for you. Even sometimes hearing that "you look really good" can be disheartening, but rather I appreciated hearing "you may not feel good, but you look really good considering what you are going through". Any sort of validation of what challenges you are going through, rather than words of tough love. And I'm not just picking on healthy people, sometimes other chronically ill people can make comments to other ill people that can be destructive, such as comparing "their sick to your sick"...yes it is a thing! And believe me that was one competition I never wanted to win, so I practiced avoiding people that would do that while sending them positive vibes and prayers. On the other hand, I have also had folks in the chronically ill community that have been very compassionate towards others and compare notes with each other in order to help in any way that they can. Individuals that administer Facebook pages to support others, even when they are going through health challenges themselves; those people should get a golden star!! One of the most encouraging things I ever heard was from a friend also having her own health

challenges, and she said, "I know you SJV, I may not know what you are going through, but I know YOU. And this must be really bad..." and I felt really understood. Like the "old me" had not been forgotten, and the "sick me" was being accepted. Also my husband has been another super star in this, even though it hit us so early on in our marriage, he has shown me unconditional love and has always believed how bad this has been, while just taking it a day at a time with me. Knowing that I already beat myself up about it and push myself to the limit, he has not taken it upon himself to do that even though he could. We also have light moments and laughter which really helps our situation, he has a great sense of humor which I thank God for every day, otherwise we would be crying more than laughing!

This isn't to say that there aren't things that the chronically ill can also "be" for loved ones around them. Most of the time we become part of a dynamic where we are on the receiving end since we are ill, but that doesn't mean that we can't still help loved ones around us better "deal" with what we are going through. Loved ones feel helpless and that is a tough position to be in. That is why, it is good to let them know how helpful they are being when you have the strength to do so. Also, sharing with them, that you still have hope that you will get better and not giving up. There is a reason that ABC Chronicle stories on the news feature ill people but will always have a positive twist to their story. We all need hope, whether the situation is hopeful or not, we need to believe that healing could happen, that miracles are possible and one of them could be ours. Even if you don't feel it all the time, try and give loved ones a sense of hope; show them that you are trying your best with the cards that you have been dealt. Figure out which loved ones can handle the details and who can't.

As the years pass, and if you remain chronically ill, keep in mind that you are still growing and changing due to both experience and age. Also realize that people grow and change around you, and someone you least expect may surprise you with enlightened compassion. I remember feeling desperate as my nieces grew up so fast while I was ill, and I was worried that they recalled less and less about their "healthy Aunt". But then I realized, children can be the most understanding and accepting resilient little human beings out there and they loved me for just "being" there, imperfect and all. Despite the stillness of your illness, keep that thought that nothing is ever constant. That is what keeps me going, despite hiccups along the way, and yes it does help to stay positive when you can. But know this, whatever your feelings, your mental or physical health, or your "being"; always practice self love and be accepting of what you are going through, even at your darkest moments. Just don't remain in the dark for too long because you deserve and need some sunshine. And despite the general judgmental nature of society, practice less judgement and more kindness to yourself and others.

“Illness humbles you”, as my brother who is a recent transplant patient, has said to me. Let us as a society be humbled and kinder to others because we have no idea what someone else is going through. Let us be okay with being perfectly imperfect and allow others and ourselves to just “be” human beings as well.

Thanks for indulging my opinions and reading my piece, I am very moved to share my experience with you.

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