The Road to Lupus Acceptance

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Moving from Lupus Denial to Lupus Acceptance

Have you ever found yourself simply closing your eyes and wishing something would just go away? Perhaps you have found yourself wrapped up in a false reality pretending that everything is okay. I certainly know I have. Denial can be a devastating position — this I know from personal experience.

I remember it well. My ‘problems’ began during the summer of 2006 — strange symptoms I had never experienced before. They were annoying, but I ignored them for as long as I could. When I finally saw my first rheumatologist, my lab numbers spoke volumes. Something was wrong.

My doctor didn’t seem to take my condition too seriously, so I certainly did not think I needed to. He was hesitant to give me a diagnosis — in fact, he really didn’t. He said, “Let’s just call it lupus until we come up with something better.” Well, okay. Life goes on and everything is peachy, right?

Well, not quite. In my mind, I didn’t really have much to worry about. I didn’t think it was a big deal.

I wasn’t as compliant with my medication as I should have been, and over the years I paid harshly for that mindset. When I think back now, I realize that it may have been a necessary process for coming to terms with my illness.

At one point the doctor said, “At least you know what you will probably die from — we all die from something after all!” Hah! *Was that meant to be funny?*

At any rate, I continued down the same path of denial. My life was right where I wanted it; I was an effective elementary school teacher with an advanced degree and planned to excel in that field until retirement. I didn’t have time to be “sick.”

I was a single mother and had a lot on my plate. Like many others, I was not accustomed to putting my needs anywhere near the top of the list. Other things were far more important — at least that is what I thought, and it worked for me for a while…

'You are VERY sick'

Then, in 2012, I saw a new rheumatologist and the truth struck me hard in the face. I was in acute kidney failure and my lupus was severe. I remember when she told me; she held my hands and looked in my eyes and said, "You are VERY sick.” *Very?* What does that mean?

Well, my teaching career was over and life would never be the same. I had advanced lupus nephritis and suddenly I realized that it *was* a big deal. I must admit that I was angry with myself — I kept thinking that if I had taken it seriously from the beginning, perhaps it could have been controlled.

Perhaps it wouldn't have advanced to this level of severity. I realized the denial I had been, and I knew that something had to change.

Just as losing a loved one can cause a downward spiral of emotional turmoil, so can the discovery of a chronic illness. Gaining lupus acceptance does not just happen — it is a process that must be experienced.

Often times, the emotional reaction to the illness can be more disabling than the illness itself and it is only through the adjustment process that we can truly embrace the new person we have become.

Regardless of the severity, lupus *will* change you. The illness manifests itself in a number of physical and emotional challenges (like having to deal with lupus *and* depression). We discover limitations that we never expected, energy levels and well-being may decline, medications become a priority, and doctor appointments seem unending.

I can remember saying to my mother many years ago that if I ever depended on medication to live I would probably die, because I just didn't do well with medication. Clearly, changing my mindset was essential.

The process of grief is not limited to just death and dying, as those with chronic illness go through a similar process. All five stages may not be experienced by all people and the order of the stages is not absolutely linear; however, the ultimate goal — and the final stage — is acceptance. It can be challenging to adequately deal with our condition until this final stage is accomplished.

Stage One: Denial

Most people will experience this stage when first diagnosed. We might consider it a coping mechanism of sorts.

It is important to note that this is a natural reaction; we are likely overwhelmed with what we are learning and by blocking out the facts, we may be better equipped to deal with the initial shock. I spent the first six years of my illness in this stage.

When considering chronic illness, this stage can be detrimental, as we are more likely to pretend the illness does not exist and therefore not decisively seek the medical treatment we need. I was non-compliant with medication, skipped doctor appointments, and had a "no big deal" attitude that did not suit me well.

Certainly, we may revisit this stage from time to time, but it is of great importance that we do not take up permanent residence in this stage!

Stage Two: Anger

Everyone has experienced anger at one time or another and those with chronic illness are no exception. In fact, some will argue that anger is one of the most common emotions that we (as humans) are most accustomed to dealing with.

It seems to (almost) be an essential stage in the healing process because it allows us to explore the depths of our feelings and get them out in the open.

In my case, the anger I felt was primarily towards myself; however, it can be extended to family, friends, and even the medical community delivering the devastating news or providing treatment. We might find ourselves saying, "This isn't fair!" or questioning, "What did I do to deserve this?"

The anger we feel may be irrational at times and it is important not to allow a victim mentality to take over. By all means cry, scream, do what is necessary to cope, but be willing to open up to someone who can help you through this stage if needed.

Next page: Moving through the five stages of grief after a lupus diagnosis.

Stage Three: Bargaining

Just as the name implies, this is when we find ourselves attempting to strike a deal — with God, a higher power, or even the doctors committed to our care. This is also a stage of “if only” or “what if” statements and we might find ourselves dealing with feelings of guilt. This was true in my case as I often wondered if the outcome would have been different “if only” I had taken it seriously in the beginning.

After dealing with anger and irrational thoughts, bargaining is our attempt at rationalizing the situation and regaining control. Certainly, we want to protect ourselves from the pain of our new reality and the unchartered territory of our condition, but ultimately our purpose here seems to be *asking* that the illness not completely ruin our lives.

We are willing to do *anything* to have the situation change — or at least that is what we wish to proclaim. Obviously, this willingness to do *anything* is not completely realistic, but it can motivate us into receiving proper treatment.

Stage Four: Depression

Although the stage of bargaining may motivate us to receive treatment, the depressive stage may halt that motivation in its tracks. As the reality of our condition sets in, we may become overwhelmed with feelings of helplessness, emptiness, and sadness. This is a natural response to loss, and chronic illness is certainly a loss – the loss of what our life once was.

You might find yourself withdrawn during this stage, as I did. There were times I wondered, “What’s the point? I’m going to be sick forever, so why bother fighting?” It is important to recognize that these are normal feelings, but we cannot let them control our outlook on life.

Often with depression comes anxiety. We may find ourselves worrying about insurance, medical bills, social situations, the inability to live up to expectations, or the course our future will take. I found that being open and honest about these feelings helped combat them and my doctor was reassuring and helpful.

Being depressed or feeling anxious does not mean you are unstable or mentally ill, and experiencing these feelings may very well be necessary to healing. We are human and those around you may understand your feelings better than you realize.

Stage Five: Acceptance

This stage is the ultimate goal and yet I believe it is greatly misunderstood. Accepting lupus does not mean that we are suddenly okay with being sick.

In fact, I’m not convinced that is even possible! I do not think I will ever get to the point of thinking it is *all right*; however, I can acknowledge the reality of my illness and come to terms with it.

For some, this is a peaceful state and an opportunity to find new enjoyments in life. The reality of the situation is that I am sick and my life looks different than it did before, but that does not mean it no longer has purpose. Through acceptance, we may find a new outlook on life. We make adaptations and gain a better understanding of what we are faced with.

This stage also provides a renewed spirit and a willingness to fight. I have become knowledgeable about my illness, see my doctors regularly, and take my medications appropriately. I have a lot to live for and I appreciate small victories.

Lupus is a condition I have, but it does not define who I am. By ultimately accepting my new life, I have a greater appreciation for all it has to offer. As a result, an abundance of learning and growing opportunities have arisen that I would never have experienced otherwise and I am grateful each day for that actuality.

Embrace who you are and all you have to offer. Recognize that you are an extraordinary person and take the opportunity to spread lupus awareness to those who have no knowledge of what lupus is. By doing this, you can effectively bring meaning to your life and potentially find that acceptance is a far more desirable stage to endure.