Coping With Lupus Stigma

by ELENA ANCIRO

How to Deal With Lupus Stigma

In the late 16th century, stigma was a mark made by pricking or branding. Today, the *Oxford Dictionary* defines stigma as a mark of disgrace associated with a particular circumstance, quality, or person.

Despite having an "invisible illness" like lupus, you can often feel like you have been marked, a target for ignorant remarks and judgement from strangers, co-workers, and even family and friends.

This internalized, anticipated, and experienced stigma can be detrimental to your mental and physical health. According to the *International Conference on Stigma*, "stigma destroys a person's dignity, marginalizes affected individuals, violates basic human rights, markedly diminishes the chances of a stigmatized person of achieving full potential, and seriously hampers pursuit of happiness and contentment."

"You Look Fine"

When you don't fit someone's vision of what a sick person looks like, it can be difficult for them to process that you are actually in a lot of physical and emotional pain. Usually, this manifests in comments like, "it's all in your head" or you develop a reputation for being a "whiner."

The constant barrage of doubt from others can eventually erode your own belief in what you are experiencing. You start to ask, "what if it really is just in my head?"

You might start to cross off things on your list to speak to your doctor about and ignore symptoms. You might stop going out as often to avoid having to explain your condition to others.

Negative Impact on Social Life

Lupus is very unpredictable; you can feel great one day and the worst you've ever felt the next. Canceling plans last minute is one of the unfortunate realities of living a life with lupus.

Some people can perceive this as a personal slight, a "convenient excuse," or they do not believe you at all. This can result in strained friendships or romantic relationships.

Submitting to the pressure to go out can lead to an increase in flares and the potential of conflict with others and losing intimate partners can deter you from engaging socially.

Fear of Disclosure

Deciding how, when, and to whom you should disclose your lupus diagnosis is a struggle. The fear of a negative reaction and impact at work or in a new relationship are common among people with lupus.

At work, you are scared that your boss and co-workers will see you differently, that they will feel you are less capable, that you are weak, fragile, and even lazy. You are concerned about being eligible for healthcare/disability and ultimately, you are fearful of losing your job.

Even outside work, it is hard to know how much to reveal to others. The dreaded, "what do you do?" question at a social event can be excruciating for someone whose work life has been affected by lupus.

Starting a new relationship is hard for everyone, but when you have lupus, it can be a nerve-wracking decision when it comes to revealing the full extent of your illness. The fear can prevent you from seeking out new romantic connections and result in lower self-esteem.

How to Cope With Lupus Stigma

Dealing with the stigma that comes with having a chronic illness is just one more challenge you have to deal with on a daily basis. As with other difficulties that come with lupus, the worst thing that you can do is to isolate yourself.

Connect With Your Lupus Community

It may feel like you are alone, but there is a large community of lupies just like you who are navigating the same fears and who have the same questions. There is a wealth of knowledge in online support networks like *NewLifeOutlook*, in Facebook Groups like *Hot Chicks With Lupus*, and other social networks like *My Lupus Team*.

There isn't a scenario or question that I haven't seen posted, nor have they received anything but an influx of advice, support, and love. It's true that at the end of day, some people won't ever understand, but believe me, there are definitely people out there who do.

There's also an endless list of lupus bloggers like me, who are determined to ensure that all the lupus warriors know that they are not alone!

Align Yourself With the Right People

There are people out there without lupus who will listen, who will try to understand as best as they can, who will bring you chicken soup when you can't go out instead of making you feel guilty. These are the people who will advocate for you and who will give you the support you need to have a happy and healthy life with lupus.

Share & Speak Out

Your experience is not in your head. It is real, it is valid, and you should not have to feel ashamed of something you have not chosen and cannot control.

Seek out a counselor or another neutral, third party to express your frustrations with the stigma that you perceive and experience. You can also choose to share your experiences as an advocate for people with lupus.

If we don't talk about it, the stigma will continue, positive coping strategies will not be passed on, and the general public will remain uneducated. We live the truth of how lupus can affect a person's life and it's important that our voices are heard.