Rethinking Your Goals After a Lupus Diagnosis

by ANNA SCANLON

Re-Evaluating for Life With Lupus

Being diagnosed with lupus, especially as a young person, can be completely devastating. Not only does it mean that you'll be on medication for a lifetime (well, for most of us), it also means the daily symptoms you're experiencing aren't going away.

Depending on the person, this can range from debilitating lupus fatigue to painful arthritis, with some days being better than others.

One of the big issues of life with lupus is its unpredictable nature, meaning one day you could be back to your old self, and the next curled up in bed all day with a fever, tea with lemon and a backlog of Dr. Phil episodes. Because of this, many young people diagnosed with lupus have to rearrange their entire lives; sometimes even changing the vocation they had dreamed of since they were children.

Although some people are able to carry on working as normal, others find that this is no longer an option. And I was one of them.

By the time I was diagnosed with lupus, six years after first experiencing symptoms, the fatigue, fevers and flu-like symptoms I was experiencing were so debilitating that I had already accepted that my life was going to be severely altered because of it.

As a child and teenager, I loved the theatre. Perhaps I wasn't the most talented actress or singer in the world, but I did have a lot of fun. Like every theatrically inclined child, I wanted a career on Broadway, but due to my fatigue, even community theatre as a hobby gradually became impossible.

There were lots of other professions I considered as well. I went through phases; I wanted to be a psychologist and then a medical doctor (although getting a D+ in freshman biology kind of made me realize that was unlikely). In college, I took my lifelong interest in history and the Holocaust and decided I wanted to be a human rights lawyer.

But it had become obvious that a 9-5 job (at least as a long-term thing), wouldn't be something I would be able to do. It would be too difficult for me, leaving me utterly exhausted and unable to enjoy life beyond working — I can imagine I would come home at 6, fall asleep, and not wake up until 8 the next morning, just to do it all over again).

On the other hand, my fevers and flu-like symptoms would mean there would be way too many days when I would miss work, making me unreliable, no matter how good I was at my job. These revelations made me have to rethink my entire life course, something that happens often to people with lupus.

Making a New Life Plan With Lupus

Instead of being a human rights lawyer, I have decided to pursue a Ph.D. in Holocaust history, although I have had to make some adjustments to fulfill that dream. Instead of going to school in the US where teaching is a requirement for a Ph.D., I decided to get my degree in the UK.

Although this means I do have to pay out of pocket, it also means I can work at my own pace. And instead of a grueling teaching schedule, I teach courses on the Holocaust online through American universities. This allows me to gain experience while grading papers and student responses in my own time (within reason, of course).

Additionally, I work on a blog that gives me a good chunk of passive income, and I thoroughly enjoy doing it. In the future, I'd like to continue teaching online and/or teaching a few classes in person each week, in addition to working as a freelance educator with theatre companies, schools and museums.

However, settling into this career path hasn't always been easy. There are so many things (like participating in amateur theatre) I am unable to do simply because my illness makes me unreliable. And this is a really difficult thing to come to grips with, especially if you are diagnosed in your 20s or 30s.

It can feel isolating as well, as many of your friends are constantly complaining about how exhausted they are after juggling a 9-hour work day, two-hour commute and then working out or doing whatever their favorite hobby is at night. This is the worst to listen to for me, because I would do anything to be able to have a life like that.

Like many other lupus patients, I worry a lot about the future and whether or not I'll be able to make ends meet or create a sustainable income with the career path I've carved out for myself. I wonder if I'm going to be living in my parents' basement at 40 and the sheer horror of that scenario makes it difficult to be completely okay with the fact that a 40-hour work week is out of the question.

Next page: rethinking your goals can be heartbreaking, but freeing.

Heartbreaking, But Freeing

For some people working with lupus, a 40 (or more) hour work week is totally feasible. As long as they control stress and stay on top of their symptoms, they can be reliable workers and it won't upset their health too much.

Unfortunately, that isn't the case for many of us, and that means rearranging our dreams. This can be totally heartbreaking and crushing, especially if you have to let go of a dream you've had your entire life because of lupus.

But it can also be strangely freeing. It means that you, and no one else, is in charge of your future.

What I have realized in rearranging my own dreams is that had I not had lupus, I might have been able to be a human rights lawyer, but I can't really see myself happy in that sort of job. Aside from the fact that a human rights lawyer works long hours, it would have involved lots of paper pushing and desk sitting — neither of which are all that appealing to me.

If your dreams have always included something that lupus now makes impossible, it is totally your right to be upset and throw yourself a pity party. But think about your hobbies and interests and work creatively.

The internet has opened up opportunities not previously available when it comes to career options, and if you speak to a career coach or a career counsellor, you may be surprised at the careers still available to you. These options can include freelancing, part-time work with a work-at-home supplement or a complete work-at-home role, making it possible to be financially independent and working around your pain, fatigue and sickness.

And if your passions involve something you can no longer do because of lupus, there are always ways to stay involved in what you love. Although I can no longer act, I will always have a love of theatre and I will always stay involved.

I take dance lessons once a week, periodically write plays or help others write plays, do dramaturgy work (researching a play, specifically the era it takes place in or the culture of the characters) and am always up for the role of an audience member.

While there are things I would love to be able to do, I am trying to see the bright side. Even if that bright side means there is more uncertainty in my life than there is for “healthy” people, no one is promised anything, really. And living with lupus often means learning to accept that.

Things to Consider

If you are rearranging your life goals due to lupus, here are some things to consider:

- **How severe are your symptoms and how many hours a day you can realistically work?** Can you work full-time if you’re at home? Part-time outside of the home?
- **What is your daily level of pain?** This may mean you will have to scratch off previous career choices that involve either a huge amount of typing or that involve you on your feet all day. However, for some people, neither of those are a problem.
- **If you plan to be on disability or remain on disability, you need to double and triple check how much extra income you are allowed to make while still receiving your benefits.** Carefully weigh whether or not it is worth it to continue on disability or if you should work to make up the difference. This is a decision that should be made after consulting with your rheumatologist as well as observing yourself in daily activities.
- **If you have to choose a whole new line of work, begin to think about what you are qualified to do and about your hobbies.** Make an appointment with a career counsellor to discuss your options. If you have to go back to school to earn another degree or credential, don’t overdo it. There is nothing wrong with taking one or two classes at a time and taking it slowly. You may even be able to earn your complete degree or credential online, allowing you to complete work at your own schedule throughout the week.
- **Remember, most get rich quick schemes are not real.** If you are looking to be employed online, there are plenty of legitimate places that will hire you to work from home, that will either pay you a reasonable salary or build up income over time. Be very vigilant and aware of work at home scams.