Moving Past Lupus Self-Doubt and Guilt

by BARBARA LEECH

It's Time to Let Go of Lupus Self-Doubt

I think everyone experiences periods of time when they think, “What am I doing with my life?”

However with lupus, these thoughts are fueled by a disabling inability to do normal, expected activities, and maybe even to stay at your current job — one you worked very hard to get.

Let’s face it, what we achieve with our work, be it title, solid income, or both, can play an impactful role in how we view ourselves. It often affects how others see us as well.

It is a part of that often-elusive thing we all seek called self-esteem, which takes a serious beating when you have lupus. You feel like whatever you were meant to become…well, lupus has side-tracked you and your dreams.

But Lupus Self-Doubt Goes Deeper

All of this disruption to your life is undoubtedly increased by the guilt and the strain lupus puts on your relationships and the feeling that you are half the person you should be to your kids, your spouse, your friends and family. You feel stretched to breaking point, yet you know you are only performing at half-capacity.

Added to all of this, you probably find that your train of thought is often derailed by lupus brain fog and you find yourself stumbling to remember appointments, your PIN number and even how to spell certain words correctly — ones you know with certainty that you know how to spell.

Heck, sometimes I have trouble remembering which child’s name I need to use. Admittedly, I have four children, but the kids probably do not appreciate being called the wrong name — especially if it is also the wrong gender.

Then there is the cold weather and all the things I cannot do or avoid doing with my kids because it places me outside where lupus and Raynaud’s (and my thyroid disease) makes my body hurt like I am being burned alive by an icy-fire. (Those who do not have lupus do not understand my term “icy-fire,” while those with lupus know *exactly* what I am talking about.)

I feel I am failing a bit as a mom. My kids will probably not have a memory of me building a snowman with them this year. No, I do not want to build a snowman. Thanks a lot, *Frozen*, for making that a common phrase around my house.

What Can We Do?

So what can us warriors do when it feels we are not who we are supposed to be; when we question what are we doing with our lives?

I believe there is action you can take each day to feel that you possess some control over who you are, who you become and the purpose your life has.

Reclaim Your Purpose

I think the root of all these feelings of being lost and overtaken by this disease is that we succumb to defeat on some level. Even if it is just a little. Yes, we are battling for our lives, but that little voice inside us asks sadly, “Where did the old me go?”

When you feel that, it triggers a level of defeat somewhere deep within you. I think we need to grieve for the loss of our old selves, then reclaim a new beginning of who we are now.

Focus on your strength, your courage, and the ways that you keep pushing on. Maybe your purpose is to serve as an example of strength to others.

Maybe it is so someone else dealing with chronic illness does not feel so alone. Maybe you are supposed to lead by example. How can we not be proud of that kind of legacy?

Maybe there is greater purpose to your life than the typical everyday achievements that you accomplished before lupus. Maybe those things don’t mean as much as we think they do.

Next page: growing to recognize our purpose and moving on from lupus self-doubt.

What Can We Do?

Do What You Can and Be Proud of It

I used to have an impressive job title. I could not do that job now, simply because of the long hours and level of stress that went with it.

If I tried, I am certain my health would suffer for it. I work from home now. It took years to build my freelancing workload up so that it provides enough, and finally I am pretty close.

I command myself to take pride in that. I am enough. I worked hard for eight years to be where I am. Just because it is not as “impressive” to the outside world shouldn’t make me question my achievements and value.

However you manage your work or even if you can no longer work because of lupus, never measure your value by this factor. Never.

Judge Your Parenting Gently

I am guilty of judging myself pretty harshly as a parent. I don’t want any of my children to feel I was not there for them, yet I know there have been times I was not. I feel guilt. Letting this go is one of my biggest challenges.

My mother had health issues since I was 13 years old and most of the time I sort of raised myself. I actually spent a lot of time caring for her, rather than the other way around.

Somewhere inside of me, that lost little girl is fighting against becoming the same kind of absent mother she grew up with.

But there are times I have failed at this. Lupus has me fighting against this absentee feeling almost every day.

There have been times when parenting with lupus has been too much and I have withdrawn into survival mode and let things slide. Sometimes you just need to try and get through the day and, honestly, teenagers can give

you challenges that even a healthy person would want to run from.

I judge myself harshly about those times. Did I say the right thing? Did I make a difference to them? Did I say too much and hurt them? Was I kind while I was being firm?

This can occur with little ones too. I struggle with bedtime often and by the time I am done reading a story and turn out the light, I cannot bear the endless questions they ask designed to keep me there longer. I get cranky. I hate myself for being cranky.

But with lupus I think we need to cut ourselves a little slack. We are human. We can apologize for being cranky and then let it go.

If you are doing the best you can as a parent and self-evaluating your actions on a regular basis, then you probably are a great parent, despite the challenges of lupus. Stop judging yourself harshly.

Growing to Recognize Our Purpose

I believe that when we look back on our lives, what will matter most is if we made a difference in the lives of others; if we took our endless challenges and used them to become more.

That does not mean a corner office or a grand job title. That does not mean pretending our challenges did not exist.

It perhaps means we advocated for others with lupus. We used our voice to spread awareness so that a cure might someday be found. We raised money for research. We shared our heart with the people we loved and cared about.

Not some grandiose physical ability or agility — just our heart. People knew that we loved them.

What we are doing with our lives can be so much more that it was before lupus because it goes to a deeper level of importance, hopefully one you will grow to recognize and make your own.