



.....

My Top **5**

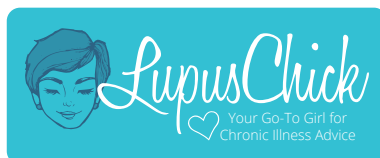
Go-To Tips for

Living Well

with a Chronic Illness

.....

By Marisa Zeppieri-Caruana



5 TIPS FOR LIVING WELL WITH A CHRONIC ILLNESS

The truth is...I could probably list hundreds of tips for living well with a chronic illness. I've learned my fair share over the past 15+ years since being diagnosed with Lupus and Urticaria. If you have been living with a chronic illness for a decent length of time, you most likely have your own set of tips to live by. However, if you are newly diagnosed, you might have a lot of questions and a million thoughts running through your head.

If this sounds like you, remember you are not alone. We were all at the beginning at some point.

It was that beginning point that prompted me to start LupusChick.com back in 2008. I dreamed of an inspirational place people could go for answers, advice, humor, recipes, life hacks and more. And tips...lots of tips on how to navigate the choppy waters that make up chronic illness.

Here are five of my favorite tips I try to remember...well, at least when brain fog isn't kicking in!

Have any questions or just want to say hello? Feel free to contact me via the LupusChick website. I love receiving and responding to mail. Also, keep an eye out for a discount coupon down below!

Xoxo,

Marisa Zeppieri

Founder, LupusChick.com
Certified Nutrition Coach & Plant-based Chef





TIP ONE:

DON'T DISCOUNT THE BENEFITS OF JOURNALING

"Marisa, you should really be journaling all of this," my husband repeated to me for what seemed like the millionth time. My poor, sweet husband was actually giving me great advice, but I was crabby, in pain and didn't want to hear it. Instead of seeing at the time how valuable this advice was, he was reminding me of an old, naggy housewife.

And did I mention how stubborn I am?

Finally, in an attempt to stop the reminders, I picked up a daily appointment calendar from Staples and started my own attempt at journaling. I didn't write long memos. Instead, I kept it short and sweet, listing the meds I took that day, any symptoms I was having, foods I ate, any activity I did, Dr. appts, and if any stressors were encountered (for me that included sun, heat, exercise, etc.)

Over time, I began to see solid patterns...and finally, some answers. I realized intense heat or more than 10-15 minutes in the sun always led to mouth and nose sores, fevers, and possibly a rash. Certain foods made my symptoms worse, and a lot of salt and sugar always gave me additional body pain the following day. Emotional stress always resulted in fevers for days. Patterns were finally starting to emerge.

In addition to health insight, journaling was also an opportunity for me to see how far I had come over the years. I think we often get bogged down in our daily life that we forget as chronic illness patients how much we do and how much we have succeeded. If you do not know my full story, there was a time years ago when I almost died. I was left in a wheelchair for almost a year, unable to feed and bathe myself. It was an awful period.

I found one of my journals recently that was written around that bad season. In one of my daily notes, I wrote: "Goal for today: To walk in the house unassisted for 1 minute." It all came flooding back to me. I haven't used my wheelchair in years and today I go swimming and to the gym when my body cooperates. But back then my main goal for the day was to try to get out of the wheelchair and walk unassisted for a minute!

I forgot these little instances, but my journals remind me.

This is one piece of advice I stress to anyone with a chronic illness. So, before I become your nagging friend, please consider grabbing a daily calendar and jotting down notes here and there. I think you will be pleasantly surprised by all you learn over time!



TIP TWO:

DON'T BE HESITANT TO SAY "NO"

I know this isn't some groundbreaking piece of advice, but it may be a piece of advice you need to be reminded of. I like making people happy, and one way I would do this was to say "yes" to everything that was asked of me. Then chronic illness came into my life, and I realized the more I said "yes," the more stress I was under...and the worse I felt.

I was also in denial, believing I could still do life exactly the same as I did it before I became ill. I couldn't. But I didn't see that right away. And so, I ran around burning the candle at both ends and did everything and went everywhere that was asked of me. Eventually, I had a massive flare up – and as I mentioned in Tip One – almost died.

Today I believe saying "No" is one of the most powerful and healing skills you can learn. Will I miss some events, possibly a birthday or wedding... perhaps. Will I choose a nap over responding to work emails. Sometimes.

I know my body and what happens to it when I overdo it. I am not superwoman, and I am totally fine with that. Even though I occasionally still feel bad about saying "no," I try to remind myself that I am doing the best I can with what life has given me and I have to take care of myself.

Chronic illness does not give a shit. Excuse my French, but I'm serious! You most likely know if you overdo it, you are going to pay the price. Long gone are the days of pleasing everyone at the expense of my body.

I read once to think of "no" as your battle shield. For those of us battling chronic illness, "no" is a little gem that can help us keep some of our sanity and offer our body the break it needs.





TIP THREE:

UNDERSTAND NOT EVERYONE WILL UNDERSTAND

For many years, I spent a lot of energy (that I really didn't have) trying to explain my chronic illness to people who didn't understand it or really weren't attempting to even listen to me. It bothered me that they felt I wasn't really sick or thought I was just being lazy. Why did I have to prove to someone how sick I was? Were my IV treatments, hospital visits and chemo not enough? Well, for some people, it wasn't. And that is okay.

It isn't our job in life to prove to people that we are fighting for our lives everyday. The people who do care and who do understand will be there for us. The others will eventually fall to the wayside. And while it may hurt at times, we have to remind ourselves to spend our energy on important things, like taking good care of ourselves. Being kind to our body, our mind.

Chronic illness can often take away so much. It breaks my heart when I see men and women inflicted with so much pain because someone doesn't believe them or understand their illness. When I see this happening, I try to encourage them with the fact that there are SO many people out there who do get it – who are living the same journey.

If at anytime you feel like you are alone, feel free to reach out to me, or stop by our Facebook or Instagram page. We have built a strong community of chronic illness warriors who support and encourage each other every day. And most importantly...who understand what you are dealing with!





TIP FOUR:

ASK FOR HELP

I was honest with you earlier about how stubborn I can be. I also do not like asking for help – because I can do it all...right? Well, in my head I like to think I can do it all. But I can't. When I try, I fail miserably.

It took me a long time to admit it. And there are some amazing people in my world who offer to help me out with things like cooking, grocery shopping, sitting with me at treatment, picking up my medicine, and even taking my rescue pup on an adventure when I need to recuperate. I finally starting taking these people up on their offers and it took a huge weight off my shoulders.

It isn't easy to ask for help. None of us want to feel like we are burdening someone else with our problems. But, if you have people who love you in your life and are asking you what you need help with...tell them. It is okay to lighten your load once in a while.

Think of it as an act of self-compassion. Your body will thank you for it. <3





TIP FIVE:

THANK OTHERS

When I am in the midst of a flare, I can get pretty irritable. In fact, downright scary. It is during these times, I try to stay away from just about everyone but sometimes that is not possible. So, when I am around people – my family, doctors, medical personnel, etc. – I try to be cognizant about thanking everyone. It is amazing what a simple “Thank you for helping me” can do. It can change the entire atmosphere of a home, a medical office, etc. People like to be acknowledged and praised.

Thank the caregivers in your life – whether it is your spouse, your parent, your best friend or the nurse in the emergency room. Caregivers have a tough job and are rarely thanked. They will be thrilled to hear your praise and I guarantee your heart will rejoice when you see a smile come across their face. Thanking other is truly a win-win for everyone involved.





Living life with a chronic illness isn't easy, but know you aren't going at it alone. If you enjoyed these tips, stop by LupusChick.com for more tips, advice, recipes, humor and more. Or just to spend a little time together...

If you are newly diagnosed with Lupus or have been living with Lupus and are ready to take your health to the next level, visit www.lupuschick.com and visit our autoimmune coaching section.

Don't let an autoimmune condition steal your joy. Let me help you take control of your health through my online one-on-one nutrition coaching program.

Use the coupon below for an extra 25% off your first online coaching session.

25% off Coaching

When you use coupon code:

5RCCH25