Making the Most of Good Days With Lupus

by BRANDY OSTLER

Enjoy the Good Days With Lupus (Without Overdoing It)

Although they may be few and far between, good days with lupus do happen! I'll be honest — I have actually felt guilty when I have a good day. Sounds silly, I know.

However, I'm homebound, on disability, and unable to work because lupus is so unpredictable and it has caused numerous complications for me. When I have a good day and feel almost normal, it seems I should be doing something productive — right?

Well, it took me awhile to celebrate the good lupus days without feeling guilty. When I was originally placed on disability, I felt self-conscious and I worried about what people were thinking.

I would often wonder if they were secretly judging me because I didn't "look sick." I haven't achieved remission, but my doctor has told me that even if I do — and even if it lasts awhile — my disability status will remain as it is because of the unpredictable nature of the illness, not to mention my near constant immunosuppressed state.

Lupus can strike at any time without much warning. The process of applying for disability is long and tedious. Once it's been approved, it would be silly to let it go when there is a good chance the need will arise again…and again…and again.

So, I have accepted it and know that even when I'm feeling okay, I shouldn't be trying to live the life I used to with all the hustle and bustle that came with it.

Sure, it can be fun and a great relief to pretend I'm not sick — even if it's just for one day. However, I have to be careful about not overdoing it.

Although I can tolerate more, the day could potentially end with a nasty flare on the horizon if I don't remain diligent and aware of my limitations. Ultimately, good days grant opportunities to do some of the things I enjoy doing that bad days simply won't allow!

So how do we embrace the good days without overdoing it?

Be Realistic

This can be tough. Like many, I have lofty dreams of returning to the travels I used to enjoy. I'd love to take a real vacation — go on a cruise, or spend a day at Disneyland with my family.

But realistically, I know these are things I simply can't do, even on a good day. If I get hung up thinking about all the things I wish I could do, the good day could pass right on by with feelings of depression, anger and inadequacy.

Because good days are just as unpredictable as the illness itself, it would be a shame to let one go to waste without some kind of enjoyment, but it's important to be aware of your limitations. For me, a good day means fewer aches and pains, less nausea and fatigue, and a relatively upbeat mood.

Breathing will always remain a challenge for me, so whatever I chose to do my oxygen tank must be accounted for.

Stay On Track

You wake up feeling good for the first time in a while — that's great! However, it doesn't mean it's time to slack off. I can recall many times in the past when I would stop taking an antibiotic after being sick because I felt okay.

Not a good choice! Regardless of how good you may feel, it's important to continue taking your medication as prescribed.

I used to worry about the overuse of medication or taking medication when it really wasn't needed, but I've learned the hard way that there is a reason doctors prescribe medication the way they do. If you stop taking it, you are putting yourself at risk.

Lupus medications are designed to keep things in check. If you feel good, then they are working! Skipping a few doses here and there could spark a flare or set you back a few steps.

Next page: treating yourself, having family fun, and more.

"Staycation" Time

Okay, so maybe a "real" vacation isn't possible, but that doesn't mean I can't do something entertaining locally. Think of yourself as a tourist in your city or town for one day.

This doesn't mean you should fill your day with 20 different things to do, but maybe pick one or two that fit within your limitations and give you the opportunity to get out of the house and do something different.

You might chose to go to a movie, visit a museum, explore a planetarium, take a trip to the zoo, or have a picnic in the park. If you search the Internet for "things to do in (name of city)," you might be surprised what comes up!

In doing this, I recently discovered that there are 100 quarter-horse statues located throughout my town! I can go on a scavenger hunt with my family from the comfort of my car.

Treat Yourself

Honesty, I can think of many things I should do on a good day — but why punish myself for feeling good? Normally, I feel sick, experience pain, and suffer from lupus fatigue and need to nap, so a good day will often change those circumstances.

Yes, perhaps it would be a wonderful opportunity for completing household chores that are difficult on typical days and near impossible on bad days. However, my goal is to embrace the good days with lupus (without overdoing it), so I would prefer to treat myself to something special.

Chores, shopping, or running errands could easily become overdoing it, so opt for something calm and relaxing that you enjoy. Go have a pedicure, indulge in an ice cream float, play a game with your kids, tend to a garden, or prepare a favorite meal that you seldom get to enjoy (if you like to cook).

Family Fun

Most of the time, family time is dictated by how I'm doing and feeling. I can admit that I get cranky at times, I'm picky about what we eat (due to what I can tolerate), and I seldom get to do what someone else wants to do.

I'm sure my husband and kids get frustrated that their ideas are put on the back burner for "some other time when I'm feeling OK." A good day can provide an opportunity for those "some other time" activities (within reason).

As long as it's doable, give another family member an opportunity to suggest something to do and follow through with their request! My kids might want to have a popcorn and movie night, but on typical days, I may be too tired to truly engage.

A good day is a great time to show your family their ideas are appreciated and just as important as your own. Allowing someone else to choose what you do, what you have for dinner, etc. can help ease any tension or resentment that may build up because of all things you can't do.

Even if you do not get the chance to experience them often, good days will eventually find you! Do not waste them. Embrace them, celebrate them, enjoy them!

Stay within your limitations and avoid attempting too much or wishing for more than you can do. Relax and have some fun, but remain realistic.

In time, perhaps the good days with lupus will become more frequent. If you find you want to do more than one good day will allow, keep a good day bucket list that you can easily refer to and add new ideas to as they arise.

By making a list, you will be prepared for the good days when they happen without wasting time deciding what do to and possibly having the good day tick by unfulfilled.

Have your family participate in creating the good day bucket list so their ideas are included as well. Not only will this provide a wonderful opportunity to connect and bond, it will give everyone something to look forward to the next time you find yourself with a good day on your hands. May you blessed with many!