Should You Start a Lupus Journal?

by ELENA ANCIRO

The Benefits of Keeping a Lupus Journal

I received my first diary as a Christmas present, its puffed plastic covers clasped together by a small golden lock. On the front cover, a dancing bear stood frozen among cotton candy clouds, the bodyguard to my precious 11-year-old secrets.

Twenty-three years later, I am still journaling in several different forms. It continues to be a safe refuge, a place to tell and find the truth of what is happening in my life without interruption or judgement, which has been especially helpful since my lupus diagnosis.

Self-awareness is integral to living well with lupus, which is why journaling can be a helpful tool in cultivating the physical and mental awareness needed to manage your particular type of lupus. Many people with lupus feel they don't have anyone to talk to who truly understands. Although our online lupus community is an amazing support, we often forget that sometimes, what we need most is a way to reflect and have a dialogue with ourselves.

Benefits of Journaling

A Safe Place to Vent

Writing down your feelings when you are feeling frustrated, angry or overwhelmed is an easy, guilt-free and safe way to release those negative thoughts. Leaving those thoughts pent up inside your head can cause major stress, which can aggravate your lupus symptoms.

A Way to Find the Good

Journals aren't just for the lows of life! Your life isn't just about lupus, it's important to remember that there are so many things about yourself and your life that are worth writing about.

Problem Solving and Goal Setting

By reading your entries, you are more likely to find a rational solution or pinpoint the real reason why you are feeling a certain way, and even if you don't, writing it down is a step forward in getting yourself to a different, more positive and productive place. Reflecting on your journal entries can also help you explore your aspirations and set personal goals.

Identifying Patterns

Every person with lupus experiences their own unique mixture of symptoms with different causes and effects. Journaling provides important clues that will help reveal those unique symptom patterns and preventative strategies.

Time for You

Whether it's for five minutes or an hour, writing in your journal is uninterrupted time purely dedicated to doing something for yourself. We are inundated with prescriptions and medical info every day, but there isn't enough emphasis on the role that your emotional and mental wellbeing plays in how active your lupus is.

Taking the time to acknowledge and explore how you're feeling is just as important as a healthy diet and exercise!

Types of Journals

Journaling every day can seem like a daunting task, especially for those with lupus who struggle to complete basic day-to-day activities. Here are some different ways you can take the plunge into journaling without feeling overwhelmed:

Life Events Diary

Back in the fifteenth century, when personal journals started to surface, diaries were comprehensive records of historical events and intimate private life. Diaries were written in frequently and with exhaustive detail.

That kind of journal keeping in today's fast-paced world seems impossible to obtain, but starting with recording daily events is a good way to start your journaling journey. As an added benefit, by engaging in cognitive recall, you are strengthening your memory.

Remember, it's not simply an exercise of writing down a list of things you did or what kind of coffee you bought today. What happens in your day is a starting point to exploring your reactions and feelings about what is happening in your life.

Remember not to censor or judge what you feel compelled to write. Your entries don't have to be long, it is perfectly okay to have entries that are only a few sentences!

Next page: more types of journals, and choosing what's right for you.

Types of Journals

Free Writing

You can take non-judgmental and uncensored writing to the next level by free writing. Free writing involves writing continuously for a set period of time without regard to spelling, grammar or topic.

Set a timer and give yourself permission to get anything and everything out of your system!

Gratitude Journaling: Three Good Things

I found gratitude journaling particularly helpful during my most recent, lengthy recovery from a major flare. This type of journaling cultivates a consistent practice of gratitude and is most effective when done daily, especially during depressive periods.

Each day, list three good things that happened. If you want to take it to the next level, you can also identify what part you played in making those good things happen.

The "good thing" could be getting out of bed, to getting a phone call from a friend, but regardless of what it is, it helps you find something positive to hold on to, to fight for. After about a month or two, I found that I didn't need to write my good things down anymore, I was able to acknowledge them internally.

Symptom Journaling

Symptom journaling is for recording the occurrence of symptoms and connected life events, medication, stress and exercise levels, weather, etc. There are online apps and versions that can be found or you can make your own journal by creating different sections for each type of information.

Use your symptom journal to prep for your rheumatology appointments. Your symptom journal will help you articulate what is happening with your lupus effectively and will make you a more empowered and knowledgeable patient.

Choosing a Journal

Each type of journaling can be done online on a private (or public) site, or on your computer, but I think having a paper journal is the best route. I am a blogger and share certain things in that public domain, but there is a level of censorship that comes with blogging, so certain types of truthful exploration aren't possible within that format.

Blank pages, lined pages, locked or unlocked, pocket or mega-sized, choose a journal that speaks to you. Taking time to purposefully choose a journal will make you want to write more frequently.

Create a Ritual

Writing in your lupus journal is a special time for yourself, so create a ritual around that time that you will look forward to. Buy a special pen you only use when journal writing, write in your favorite coffee shop, outside at the park you love, in bed with a cup of tea, or with relaxing music in the background.

The Importance of Revisiting Yourself

Every now and then, it is important to crack open your journals and re-read old entries. Your journals are a reminder that you are always your biggest ally, that there is always something on the other side of what you know, and that sometimes you need your past to help you build a happy and healthy future.