What Is the Lupus Spoon Theory?

by BRANDY OSTLER

Using the Spoon Theory to Explain Lupus

Shortly after I was diagnosed with lupus, a friend emailed me a link to what she referred to as a must-read for anyone with lupus. The article, titled *The Spoon Theory,* has been passed around and referenced to in many lupus groups, support sites, Facebook pages, Twitter feeds, and personal blogs for over 10 years.

Some would call it a phenomenon with a large following of people that refer to themselves as “spoonies.” So what exactly is the spoon theory and how can the metaphor be helpful to those who have lupus?

Understanding the Theory

As the story goes, Christine Miserandino, who wrote the article, is having dinner with a friend who asks her what it feels like to have lupus.

The question takes Christine by surprise because surely her friend must know — after all, she has accompanied Christine to the doctor, has witnessed her crying in pain, and has certainly seen her puke in the bathroom more than once. The friend clarifies; she wants to know what it feels like — not physically, but personally — to Christine. What does it feel like to be sick?

To answer the question, Christine grabs a bunch of spoons from several tables, bundles them together, and offers the metal bouquet to her friend with the statement, “Here you go, you have lupus.”

Her friend is obviously confused, but is certainly willing to play along. Christine explains that most healthy people expect to have a never-ending supply of “spoons” each day, but when you are sick, your supply is limited. Each daily task “costs” a spoon — and when they are gone, they are gone. She goes on to explain that she needs to know how many spoons she has to start with so she can plan her day accordingly.

At this point, Christine asks her friend to count the spoons in the bouquet — there are 12. Next, she has her friend share what she does every day.

For each task rattled off — getting out of bed, showering, getting dressed, eating breakfast — Christine takes away a spoon. She says each little detail has to be considered, and decisions are made based on her circumstances for that day; for example, if her hands are hurting, she needs to choose something without buttons to wear.

The friend realizes half of her spoons are gone and theoretically, she hasn’t even arrived at work yet. Christine reminds her friend how important it is to plan the rest of her day wisely. In order to accomplish certain tasks, others will have to go undone. There simply are not enough “spoons” to do everything.

In the end, Christine hands her friend one more spoon. She explains she has learned to keep an extra spoon in her pocket — just in case.

Applying the Lupus Spoon Theory

I like to think of the spoons in this analogy as representing energy. Although Christine's friend was given 12 spoons, there really isn't a magic number. Every day you may find you have more or less spoons depending on how you are doing on that particular day.

If you are in the midst of a really bad flare, you may only have five spoons at your disposal for the entire day. However, on a really great day, you may find you have 20 available to you.

Because of this, it can be challenging to make plans ahead of time. You have to assess each day as it comes. You can certainly schedule your day according to an average number of spoons as long as you are willing to make adjustments when necessary, but that probably isn't too much of a problem. Those living with a chronic illness tend to become experts at adapting.

Ultimately, I have found the spoon analogy is most helpful when explaining my condition to others. I know my limitations. I know what it feels like when I can't do something I want to do. I know what it's like to have to change my plans when my body tells me "this isn't happening today!"

But I have discovered that others don't know. They don't always understand. I have had to slow down. I frequently get frustrated. I often want to do more than I am able to do, and it doesn't always matter how badly I want it. The idea of "where there's a will, there's a way," isn't always true when it comes to lupus.

Last summer my sister invited me and my family to spend a day "having fun." I had to decline, and I worried she wouldn't understand.

She wanted to go to the local water park, a small amusement park, the zoo, and a miniature golf course all in one day. I could maybe participate in one of those activities, but there was simply no way I could do all four.

In this instance, the metaphor of spoons came in handy. She may have been disappointed, but at least she understood it wasn't about me not wanting to spend time with her, but rather I wasn't able to do so.

Additional Thoughts

It's important to keep in mind that the spoon theory is not limited to people with lupus. In fact, I think it can actually apply to anyone — but especially to people who have chronic illnesses or other disabilities.

I don't believe all healthy people have an unlimited number of spoons (at least that's what my husband tells me!) However, I do think healthy folks have more options for building up stamina to gain more spoons. The biggest difference is those living with chronic illnesses have learned to not take their spoons for granted — they have learned not to waste them.

The metaphor can actually work with more than just spoons. If you find yourself needing to explain why you can't do this or that, choose a concept you can relate to — something creative that can offer a tangible experience to the person you are talking to.

For instance, think of a toothpaste tube. When you first get it, it's really easy to squeeze out the paste. As it gets closer to being empty, you have to work really hard to squeeze that last bit out. Any concept of this kind can go a long way with helping others understanding the challenges, limitations and choices that have to be made every day.