

# THE SPOON BLESSING

By Rev. Joanna Lubkin

Somewhere between the French fries and the gravy, the Spoon Theory was born.

Christine Miserandino and her best friend Lauren were in the diner, talking. The two of them spent a lot of late nights there throughout college, laughing and chatting about crushes, music, or classes.

As Christine reached to take some of her medications with a snack, Lauren paused mid-sentence and stared. “What does it feel like,” Lauren suddenly asked, “To be sick all the time? What does it feel like to have Lupus?”

Christine was surprised not only by the abrupt change in topic, but also because she assumed her friend already knew everything there was to know about Lupus. Lauren had come to doctors with Christine, she had seen her walk with a cane, had seen her cry in pain — what else was there to know?

Christine started to ramble on about pills, and aches and pains, but Lauren kept pushing, unsatisfied with the answers. She asked what it felt like, not physically, but what it felt like to *be* Christine, to be sick. Lauren looked at Christine with the intense face of someone straining to see something invisible.

As Christine tried to gain her composure, she glanced around the diner for guidance. She suddenly grabbed every spoon from their Formica table, the neighboring tables, and the diner’s countertop stash.

The cold metal spoons clanked in Christine’s hands as she grouped them together and held them out to Lauren. Christine looked her best friend in the eye and said, “Here you go, you have Lupus.”

Lauren blinked back, befuddled, as anyone might be when they are handed a bouquet of spoons.

Christine explained the difference between being sick and being healthy. It meant, she said, having to make choices and consciously think about things when the rest of the world doesn’t have to. “When I was healthy,” Christine said, “I had the luxury of a life without certain choices. It was a gift I took for granted.”

“I used to start each day with an unlimited amount of possibilities and a fresh store of energy; a fresh store of spoons.”

Christine asked Lauren to count her spoons, saying that when you are healthy, you expect to have a never-ending supply of ‘spoons.’ But now, as a person with spoon-Lupus, you need to know exactly how many spoons you are starting with.” She counted

out 12 spoons.

Christine asked Lauren to list the tasks of her day, including the most simple. As Lauren rattled off daily chores, or fun things to do, Christine told her that each one would cost her a spoon. When Lauren jumped right into getting ready for work as her first task of the morning, Christine cut her off and took away a spoon, saying,

“No! You don’t just get up. You have to crack open your eyes, and then realize you are late. You didn’t sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don’t, you can’t take your medicine, and if you don’t take your medicine you might as well give up all your spoons for today and tomorrow too.”

Showering cost Lauren a spoon, just for washing her hair. Getting dressed was worth another spoon.

Lauren’s spoon supply was dwindling quickly. Christine then explained to her that she needed to choose the rest of her day wisely, since when your spoons are gone, they are gone. Sometimes you can borrow against tomorrow’s spoons, but that will just make tomorrow that much more difficult.

Christine said that a person who is sick always lives with the looming thought that tomorrow may be the day that an infection, a flare up, or a relapse strikes. So you do not want to run low on spoons, because you never know when you truly will need them.

As they went through the rest of the day, Lauren was forced to make choices and think about things differently. By the time Lauren reached the end of the day, she was down to only two spoons, and she was faced with the choice of cooking dinner, doing errands, or cleaning the house. She couldn’t do all three.

Lauren looked stunned and close to tears as she asked Christine, “How do you live like this?”<sup>1</sup>

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This is what it means to be chronically ill. This is what it means to have Lupus, fibromyalgia, chronic fatigue syndrome, depression, Crohn’s disease, and dozens of other conditions both diagnosed and mysterious.

I know, because chronic illness has touched my life and the lives of those I love.

The Spoon Theory is a window into what it means to be on the inside of an invisible disability. It is a shared vocabulary to let those on the outside *in*.

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<sup>1</sup> Miserandino, Christine. Adapted from "The Spoon Theory." *ButYouDontLookSick.com*. Web. 25 Nov. 2011.  
<<http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory-written-by-christine-miserandino/>>.

This is a sermon for the healthy. This is a sermon for those who have a loved one living with invisible pain. This is a sermon for congregants who want to be a truly loving ally of those struggling through illness and lifetime disability. This is a sermon for the teenager who just can't understand why their friend misses so much school, or know what to do about it. This is a sermon for the sick who need a way to clue in their loved ones. This is a sermon for all of us.

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The practice of visiting the sick, called *bikur cholim* in Hebrew, is described in the Talmud as a moral and spiritual obligation, important for the soul of the sick person as well as the soul of the visitor.<sup>2</sup> This is most often talked about in terms of visiting someone in the hospital or sending a care package to a friend home sick with the flu, but the ongoing support of a loved one with a long-term illness brings up a completely different set of challenges and blessings.

Witnessing another person's suffering can be tremendously difficult. It can also be a tremendous spiritual practice. It requires that we contend with our own frustration at our inability to heal the person, our sadness that they cannot always be a part of "life as usual," our fear that we may do something wrong. It requires that we release our ego and admit that we sometimes just don't know how to help.

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*Bikur cholim* is important for the soul of the sick as well as the visitor. I humbly share some collected wisdom as to how to hone our practice. These ring true for my own experience and for many others, though each person has a different experience of their illness. Our hurting loved one is our best resource.

The first thing we can do for us and for them is to show up.<sup>3</sup> Be there.

Groundbreaking studies show that social pain, such as loneliness or rejection, is processed by the same systems of the brain that process physical pain. Incredibly, the experience of physical pain can make you more sensitive to emotional pain, and vice versa. A flare up or a bad-pain-day actually *makes* you feel more socially isolated and crave social support. Studies show the flipside, too — that loneliness makes physical pain worse, while having a loved one present can reduce pain.<sup>4</sup>

I come back again and again to the elegant simplicity of Reverend Burns Stanfield's song, "Walking With You." I use it to help remind myself of my true intentions in the

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<sup>2</sup> Talmud Bavli, Tractate Nedarim. 39a-40a

<sup>3</sup> Paraphrased from Rev. Kim K. Crawford Harvie, "Good Grief," sermon preached at Arlington Street Church, October 31, 2010.

<sup>4</sup> McGonigal, Kelly. *Yoga For Pain Relief: Simple Practices To Calm Your Mind & Heal Your Chronic Pain*, page 3. New Harbinger Pubns Inc, 2011. Print.

moments when I start coming up with excuses  
for why I don't follow through and reach out to my friends who are hurting.

Walking, walking with you / walking with you is my prayer.  
Being, being with you / being with you is my prayer.

This mantra helps guide my feet to my friend's doorstep, my hand to the phone to call and check in on them. These words also remind me that, often, just being with them is enough. Being with them is good for the soul of the sick and for the visitor.

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When we care about somebody, we want to do anything we can to help them get better. We want to offer all the tools and treatments at our disposal. It's very hard for a person with a caring heart to surrender to the knowledge that the person they love may never be well. This tests our spiritual practice of surrender over and over again.

This practice of surrender is huge; let us focus our lens on one specific scenario.

Our hurting loved one has likely spent countless hours submitting their body to the expertise of medical professionals. If our loved one has already gone through it all, it is a great kindness to them for us to stop ourselves from suggesting treatments. If we absolutely must share some piece of medical advice, we can frame it in a way that shows that we know that they know their own body the best. This holding-back at a time when we see our friends suffering the most can be a huge challenge.

We can use this challenge as a spiritual practice, with implications that reach all aspects of our lives. Jewish-Buddhist teacher, Sylvia Boorstein, wrote about this practice of surrendering to what-is:

**“The core challenge in my life ... in all our lives, from beginning to end, is **accommodating to realities that we wish were other, and doing it with grace.**”**<sup>5</sup>

Even after we think we've accommodated to that reality, when we think we've finally surrendered, it's easy for us to leap into an imagined future when we see our friend having a good day. It's easy to think, “They seem well right now, so they'll be doing well later. They must be getting better.” It's important for us to remember that their good day is just that: a good day.

This can be difficult to remember with invisible pain. When we see a person who is paraplegic, it's reasonable to expect that if they were paraplegic last year, yesterday, or two hours ago, they'll probably still be paraplegic the next time we meet them.

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<sup>5</sup> Ibid.

With many chronic illnesses, though, symptoms can fluctuate rapidly — their supply of spoons may change drastically from one day or even one moment to the next.

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Another aspect of surrender is suspending our judgment of another person's well-being. The old cliché rings through here: We can't judge a book by its cover, and we can't trust a person's appearance to tell us how they feel.

On his blog "Not Done Living," Ricky Buchanan wrote a post underscoring the difference between 'happy' and 'healthy.' He wrote, "I've been sick for years. I can't be miserable all the time — in fact, I work hard at *not* being miserable. So if you're talking to me and I sound happy, it means I'm happy. That's all. I may be tired. I may be in pain. I may be sicker than ever. [It hurts when I hear my friends say,] 'Oh, you're sounding better!' I am not sounding better, I am sounding happy."<sup>6</sup>

We so want our loved ones to feel better. We so want them to be happy. In his blog post, Ricky mentioned that he works hard at not being miserable. Many people with chronic illnesses feel like they're at war with their bodies, fighting with their pain to live life the way they want to.

I truly believe this is the most critical part of the sermon to remember. Our loved one may be experiencing this inner battle with their pain.

Jon had suffered from migraine headaches since he was a teenager, but they seemed to be getting more intense. The migraines felt like a personal assault to Jon. Because the pain was inside his head, it felt both intimate and incredibly invasive. The migraine took up the entire space of his attention, crowding out the ability to do anything at all that required focus. Jon described it as if the migraine was squeezing him out of his head and taking over."<sup>7</sup>

The greatest gift we can offer our friends fighting off the invasion of pain is to **strengthen and nourish the real them**. Find out what makes our friend come most alive, feel the deepest sense of well-being wash over them, or really gets their creative juices flowing. Do that with them. Hint: This isn't just for people who are sick.

Perhaps it is yoga and breath awareness that gives Jon the spaciousness he needs to reclaim his sense of self. We can go with him to yoga class, or be his gentle cheerleader. Perhaps gardening nurtures Christine, but she doesn't have the spoons to dig and bend. We can wield the trowel.

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<sup>6</sup> Buchanan, Ricky. Adapted from "An Open Letter To Those Without Invisible Disability Or Chronic Illness." Not Done Living. Web. 2 Dec. 2011. <<http://notdoneliving.net/openletter/id>>.

<sup>7</sup> McGonigal, Kelly. Adapted from *Yoga for Pain Relief*, page 29.

As it is in so many cases, we may have come thinking we're helping someone else — but by sharing our spoons with them, we, too, are strengthened. *Bikur cholim* is important for the soul of the sick as well as the visitor.

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Here and now, this is my wish for us:  
May our souls be strengthened  
as we strengthen the souls of the ones we love.  
May we let being with each other be our prayer.  
May we share our spoons.