

In the Land of the Sick
by Rev. Michelle Collins
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“It’s going to be okay.”

Have any of you ever had this said to you? Any of you said it? Recently? When I first started out as a hospital chaplain, I’m afraid to say that this phrase was coming out of my mouth on a regular basis. I wanted to be encouraging, after all. I don’t remember how long this lasted, but I do know when I stopped. I was visiting a man with diabetes who hadn’t been managing his illness well enough, and part of his leg was about to be amputated. This was understandably devastating for him. As he was sharing with me about his fears, I felt these words forming in my mouth. “It’s going to be okay.” But I didn’t say them that time because all of the sudden I realized how ridiculous they sounded. He was telling me that it was the complete opposite. “Okay” was exactly what wasn’t going on, and the new reality he was about to face didn’t feel “okay” in any way. For me to say that everything would be okay would be ignoring the very reality of the changes in his life, the losses he was facing, and his raging river of feelings at the moment. It wasn’t okay!

“Okay” is a funny word, very subjective, depending on who is determining it and what’s going on for them at the moment. Today I want to really focus on times that aren’t exactly “okay,” when something isn’t “fine.” Thirty years ago, writer Susan Sontag wrote, “Illness is the nightside of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick... sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”¹

Illness is something that we all face at times throughout our lives, times when we have to acknowledge our dual citizenship. But many of us face as illness an on-going part of our lives, when it seems that we are only citizens of the kingdom of the sick with no respite in that other place, the kingdom of the well.

The number of those with chronic illnesses is higher than one might think. From a survey done in 2005, across the population, 44% of all Americans have some sort

¹ Susan Sontag, *Illness as Metaphor*.

of chronic condition. And the percentage is no doubt even higher today, as our average age continues to rise. That's almost half who are living with a chronic illness! And the number of those who face multiple conditions is large as well. Of those ages 45 to 64, 22% have three or more chronic conditions; ages 65 to 79, 45% do; and of those ages 80 and up, 54% would claim three or more chronic conditions.²

Take a moment and look around you. 44% or more of the people that you see are facing a chronic illness right now; and taking into account the age ranges here in our church, probably about a third are struggling with three or more chronic conditions... right at this moment.³

Each of our paths in the land of the sick are different, but they often have many similarities.

Author Joy Selak has lived with chronic autoimmune, musculoskeletal and neurological conditions since the 1990's and has written about her journey in the book *You Don't Look Sick*. Here is a little of her story:

The Seattle porch where I sit is wet and shrouded in a chilling fog [she writes]. I can't see two feet in front of me. I try to push aside the curtain of mist to peer through it, but my hand moves as if through water.

The truth is I am just afraid. I have come to Seattle for a medical test, one of a series of medical tests that only seem to raise questions without offering answers. Before this one today, there have been many other tests, resulting in no more than guesses and stabs at naming all that is wrong with me. I believe I have done the best I can to help find the answers. I have gone to dozens of doctors, read volumes of research, and sought the advice of many both traditional and alternative health care practitioners. Yet I am still so lost, so confused, and frightened. And I am still very ill.

After the test today, I am tired and hurting. I'll stay tonight in Seattle with dear friends. Sensing my despair, they gave me dinner and hugs then wisely left me alone with my thoughts, here on their dark porch.

² Statistics from http://www.naturalnews.com/025379_americans_America_chronic_illness.html

³ With the statistics noted above, applied to the age ratios in the church's current membership

I reflect that it has been seven years since I first sensed something was wrong with me and began reporting symptoms to my doctors. It has been over a year since I began a determined search to finally find out just what it is and what to do about it. I wonder if I have moved from the spot where I first began. I need someone to lead me, a good doctor in whom I can place my trust. Should that be so hard to find? Yes, my experience tells me, yes, it is just as hard to find a partner in illness as it is to find a partner in life.

That is not to say I haven't been able to find any good doctors, I have. But I don't have that one special doctor. But so far, none of my efforts, or these doctors' efforts, have improved my health, or even clearly explained what is making me so sick.⁴

The beginning of paths of chronic illnesses as well as many acute ones are often filled with question marks. When I came down with my own neurological syndrome eight years ago, answers weren't so easy to come by. The first doctor I talked with in a drop-in clinic looked at me as if I were crazy. The nurse practitioner who I saw for primary care was gratefully open that she had no idea and after plenty of research, shared a bunch of ideas before sending me home, but still with no answers. It was back to the crazy look when I ended up in the hospital, when I thought I could see the phrase "you don't look sick though" in their eyes. The beginning of my path was a quick series of events, so after two days in the hospital with I don't remember how many tests, I finally had a diagnosis. I remember experiencing relief and thinking, "See! I'm not making it all up!"

Sometimes labels and identities are easier to come by, and sometimes they aren't. The seeking though seems to be fairly universal, seeking answers, seeking allies, and repeats itself over and over again. But I think just as universal as seeking is the denial and disbelief that we often find ourselves in.

Author and former law professor Toni Bernhard has shared about her own yet unexplained flu-like illness and her own disbelief as it just didn't go away. "Each morning [Toni shares], you expect to wake up not feeling sick even though for weeks and months and for years that has never been the case. It's just so hard to,

⁴ Joy H. Selak and Steven S. Overman, *You Don't Look Sick*, pages 3-4.

first, truly recognize that you're chronically ill and, second, to accept that this illness is going to require you to change your plans for life in ways you never imagined."⁵ One of these changes for Toni meant giving up her profession of teaching law for good. She related that she continued to work far beyond what she should have in part because she just didn't believe the illness wasn't going away. These change and new realities are different for everyone. They might mean profession changes, or retirements, or giving up driving or living independently. Loss is another common landmark in this kingdom in which we all have common citizenship, the kingdom of the sick.

After my own diagnosis with a rare neurological condition, I was sent home to go about recovering. There wasn't anything specific done to treat it – they just said my nerves would gradually rebuild themselves. I had no ideally how gradual gradually would be. At first, I just waited. I waited to “get better.” I waited for it to go away. Over the first six months, my nerves did make a good deal of progress – I was able to walk up and down stairs again and to walk at all without support, and I could pick up my daughter again – she wasn't even walking yet at the time – my nerves made a good deal of progress but they never did get back to the “better” that I was defining at the time, and they haven't since either, if “better” were to mean being the exact same as Before. It took a long time for me to be able to accept that and quit feeling sorry for myself all of the time.

Our paths through the land of the sick may pass by many of these common milestones – uncertainty and seeking answers, denial and disbelief, feelings of vulnerability, losses, and loneliness. But I hope that they also pass by acceptance and grace along the way.

One of the authors I found who shared their own journeys with chronic illnesses and chronic conditions came up with the best phrase. I admit that I'm totally jealous, because I wish I could have thought of it first! But it's still a great phrase, one that I hope we can all hang on to. To cope with the stress of illness, she calls for us to find CHRONIC RESILIENCE.⁶

⁵ Toni Bernhard, *How To Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers*, pages 12-13.

⁶ Danae Horn, *Chronic Resilience: 10 Sanity-Saving Strategies for Women Coping with the Stress of Illness*.

Resilience is by definition long-term – it’s what keeps us able to cope and able to adapt to changes and challenges. Usually I might say resilience is about “bouncing back” but with a chronic condition that isn’t going away, there may not be an okay to be able to bounce back to. Chronic resilience is grace and acceptance; it’s hope that we can cope with a new normal; it’s compassion that we’re willing to give ourselves when we need it.

I see chronic resilience in a blog post about Chronic Fatigue and Immune Dysfunction Syndrome, or CFIDS. There’s a new term here too – Illiversary – the anniversary of the onset of an illness or diagnosis. Listen for the chronic resilience: “My Illiversary used to be such a significant day for me, a reminder of all I had lost. Now it just feels like any other day. Yes, my life is dramatically different than it was pre-March 2, 2002, but I have adjusted and adapted to my new normal. I’m no longer lying on the couch waiting to get better; I have since resumed living my life. It’s just a different life than it was before. I still have many restrictions and limits that define each day, but I have tirelessly researched treatments and have found several that have helped me get up off that couch and resume some version of my life.”⁷

And I heard resilience in a friend’s recent Facebook post about his Illiversary: “Day Zero [with the date] and I’m still standing 7 years later. My feet hurt, but I’m still standing.”

The pain is real; the struggle is real and on-going, but he’s still standing.

Chronic resilience takes more than one person though. My friend’s post certainly showed that, in the many supportive comments that he received in response. It takes health practitioners – both of traditional medicine and alternative therapies – health practitioners who work with trust and respect. It takes caregivers – partners and spouses, parents, family members, and friends. For those who accompany us most closely on our journeys in the land of the sick, it takes chronic resilience and support for them, too. It’s a precious and difficult job, to be a caregiver for someone who is ill and hurting, with many of its own stresses and needs. And what I’ve heard over and over again how precious it is to have the companionship of others on these journeys. We have two groups here at the

⁷ From <http://www.lifewithcfs.blogspot.com>

church of those journey companions – a group for those on the journey of illnesses called Living Well with Chronic Illness, and our caregivers' support group. In these groups stresses can be shared and understood, and journeys are a little less lonely. If you want to learn a little more about the Living Well with Chronic Illness group, they will be at the Groups & Programs table during coffee hour today.

How can we each make chronic resilience happen? I wish I knew a magic formula for chronic resilience, but I don't. If I did, then I could say "it'll be okay" without hesitation! There is no magic formula. The path to figuring out what okay might mean, what it takes to realize and resume some version of our life, as the blog post said – this is what chronic resilience is about, and it's different for every one of us. My hope is that we can find what that might be to be chronically resilient, and also that we can give ourselves and each other plenty of compassion and acceptance along the way. May it be so.