

## Care Reflection — What Do We Believe When We Cannot See?

Of the 61 million adults in the United States with a disability, approximately 57 million (94%) do not use a visible mobility device such as a cane or wheelchair. I am one of them. I have had an invisible disability, Crohn's Disease, for nearly 50 years.

A few weeks before my first year of high school, I started throwing up, experiencing acute pain in my stomach, losing weight and hair. Something was terribly wrong. Two years later I was diagnosed with Crohn's, a chronic autoimmune disease in the intestinal tract.

Per the Americans With Disabilities Act, passed 30 years ago in July, a person with a disability has "a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment", or has been "regarded as having such an impairment".

I did not learn Crohn's was a disability until 14 years ago, and I first read this in the ADA while doing research for this article: "An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active".

I walk around with a disability sequestered by skin. Without a visible cue, people seem to either not believe it exists, or believe it and forget. If my deformed intestines were located on the outside of my body, might people believe and remember?

What do we believe when we cannot see?

If those of us with invisible disabilities seek to cross the great visual divide, we need to share our stories. People do not have x-ray vision.

For my first 40 or so years with Crohn's, I repeatedly felt silenced and fell silent. I felt shame and embarrassment, not believed. My husband Cork, whom many of you know, is still hearing some of my Crohn's stories for the first time.

God sustains me. I know that I am beautifully and wonderfully made, that God will see me through, and that God has a plan for me that glistens with its light and promise. God knows what and why God does.

When I disclose my disease to someone, here's what does not help me:

1. "But you don't look sick." Well I am. While meant to support, this statement unintentionally denies truth.
2. "I had a really bad stomach ache two weeks ago. I understand." Unless you have a chronic intestinal disorder, you really don't.

Here's what does help me:

1. "I'm so sorry. That must be so hard."

2. "What can I do?"

Each one of the millions of Americans with invisible disabilities is one individual. Not all of them want the same things at the same time.

I like it when people occasionally ask me "How are you feeling?" rather than the standard "How are you?" It acknowledges that you remember. It makes me feel I matter.

Some people may not want to talk about it. I certainly didn't want to for a long, long time, especially as a teenager.

Now I do. Five- to 10 years ago an anger started to burble up inside of me, and I had grown so very weary of hiding my true self. I felt so disconnected from people.

God has taught me that "being strong" doesn't necessarily mean we need to be silent. Sometimes it means we need to speak.

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*To support or be supported by Saratoga Federated's response to the Invisible Disabilities Association's Invisible Disabilities' Week, Oct. 18-24, 2020, contact the SFC Care Ministry team at [care@saratogafederated.org](mailto:care@saratogafederated.org) or 408-867-1000 x 239.*