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By David M. Johnstone October 27, 2022

Moving from Invisible to Visible

In 1989, shortly after our wedding I was hospitalized and given a worst-case scenario of six months to live. Obviously, that did not happen. I was hospitalized with a loss of sensation from my sternum to my toes, and my left arm lost all mobility. While feeling and control was restored after some weeks, it took two years before I was diagnosed with multiple sclerosis (MS). I had the type of MS that flared up and then receded (formally known as: relapsing-remitting multiple sclerosis or RRMS). Exacerbations or relapses would occur but after a time, symptoms returned to normal.

Over the years, I had children, completed university degrees, began a vocation, and made numerous moves. My illness did not go away, and I still had recurring symptoms—but the disease was hidden. The MS was such a part of our lives that we would often forget to tell our friends. We did not hide it; we just did not think about it.

One summer evening, my college-aged sons drove by as I was out for a walk. I had been a runner but had been slowing down. Walking was the way I would process the craziness of the day. When I got home, my sons had an “intervention” with their father. They noted that I looked unsteady, weaved, and shuffled as I walked. The MS had started to affect my balance to a point where I would occasionally stagger and wobble.

For most of my life, MS has been invisible. There were bursts of time when it was rough, but most of the time it was unobserved by others. Over the past few years, my invisible challenges have become increasingly visible—they have moved to a new classification designated by doctors. My illness has become secondary progressive multiple sclerosis (SPMS). Not surprising, many who have RRMS “will eventually transition to a secondary progressive” stage over their lives. Essentially, the effects of the disease have built up over time.

I did not see myself as challenged until a few years ago. I did not recognize that I had a disability until I came across a list on a federal document outlining protected statuses according to the Americans with Disabilities Act. Weakness was and is my most common symptom. At times I do not have the strength or energy to move parts or all of my body. This is a disability.

The MS has started impacting my mobility to such a degree that it is increasingly obvious that I am not “able.” I was no longer invisible; I was visibly disabled.

A Whole New World

The breadth of what can be identified as an invisible disability is vast. Disabilities are complex and specific to an individual. The implication is that disabilities and challenges are unique, unpredictable, and distinctive. These symptoms can range from mobility challenges, processing speeds, learning differences, health dynamics, and a myriad of other considerations.

Some disabilities are stand-alone concerns, and some are a mix that build upon each other. Some individuals have a buffet of barriers that can shape their days. Some of these challenges are documented and accommodations are legally required. Some are not reported out of choice, others are not recognized, or some might not be defined.

I am relatively new to the conversation about disabilities. I did not and still do not have the right vocabulary, and there is much I do not even think of or consider. I have found it helpful to seek out those who aid, support, and notice students who have invisible challenges whether physical or neurological. (Conversations with colleagues Rick Muthiah, Andrea Byerley, and Hannah Jackson have been invaluable.)

Colleagues remind me that we are all “one step away or a half-second from having our own disability.” We are often more fragile than we want to acknowledge. Sometimes we get caught up in the idea of “normal.”

Normal is used in casual conversation to suggest the typical or usual. Unfortunately, it also becomes a standard by which anything that is not typical is not normal or fails to meet the standard. This “normal” becomes problematic because I wonder who or what sets the normal standard. Very few lives are reflective of our assumed normal. Our perception of the average, typical, common, and normal is often inaccurate and little myopic. Sadly, it also marginalizes many in our midst because they do not see how they could fit into that perceived idea of who we are as a community.

Students experience unique diseases, diagnoses, and disabilities. Our responses also require some creativity and uniqueness. One colleague asked, “Think of the last time you were late, had an accident, encountered something unexpected, and how it impacted others. Then think about the grace someone extended to you.” This simple challenge has compelled me to look at how I interact with students in general. Sometimes I default to the arrogance of “when hard things happen, then others should be able to endure like I did.” However, I catch myself and affirm to my students that things happen or have happened—and there are resources and people who will stand in their corner and advocate for them.

Sorenson noted, “Many of us live in cultures in which individual performance and independence are prized.” Asking for assistance is difficult. I (and many students) struggle with not wanting to be seen as weak, or even needy. There was a mix of pride and shame in my hesitations. There was also concern that I might be perceived as no longer being able to do my work, my vocation, my role in the kingdom of God.

As I began to inquire about the experiences of those with invisible disabilities, the feedback from students is that they were not always believed or understood. Sometimes they were actually confronted with disbelief. Social stigmas were a challenge as were misunderstandings about their specific challenge. Others cannot readily see the pain, the shaky balance, the inability to grasp words, the blurry vision, the weariness of fatigue, or even the sadness.

When a student trusts you with their story, do not dismiss them when they bravely come to speak with you. Be trustworthy—they are taking a risk. They are sharing precious pieces of themselves with you; respect and honor those things they share. Scripture speaks of not casting “your pearls before swine, lest they trample them under their feet” (Matt 7:6). Simply stated, don’t be the swine that tramples students’ precious things.

Not everyone will require accommodations. Not everything may be reportable according to institutional disability services. Ask what the student needs. They may not need anything; they may just want your awareness or trust. Encourage them to connect with your disability services offices. Regardless, there is no cost to being kinder than necessary.

Imago Dei?

The challenge is that in spite of my disabilities, I am still made in the image of God (Genesis 1:26). Sometimes I do not believe this. At the same time, I sometimes fall into the thinking that God is similar to me. I ascribe human tendencies, in an anthropomorphic way, to God.

The word image has often suggested to me similarity or copy of something. When I thought of God and his glory, I very much knew that I fell short of his glory (Rom 3:23). A few years ago, Lane made an observation about imago dei (image of God). This understanding helped me process that idea. He wrote:

The word “image” refers to a “likeness” or even a “shadow” of someone else. So, Israel was told not to create “images” of God as other nations were prone to do, because if they did so, they would probably get His nature wrong. They were to do without human-made images (idols) of God as a means of connecting them with God. Instead, God gave them something else, the very people around them (made in His image) and God’s occasional manifest presence. These gifts were to be enough for them to experience God’s “shadow” as a means to see and experience God Himself.

The notion of shadow or even hint of the divine within human beings is thought-provoking and personally a corrective understanding of this theological assertion.

Not So Final Thoughts

I would affirm that our students’ stories are theirs to tell. It is a sign of respect to them that they have control over their own story. They should not assume others know their story. It is risky, but they might want to allow others a glimpse into their life, and they may be surprised at the number who will stand in their corner with them.

I may not be able to do some things I did previously of my past, but I can still do many things and have discovered new abilities. I am hopeful that these abilities will be restored—maybe not

until heaven. Currently, my feet are still on the ground and are still moving; one day that may stop. While challenges rarely stop, the kindness of God and the community that surrounds me is experienced daily.



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