Breaking Barriers

everybody belongs • everybody serves

Winter 2017 (Disability and spiritual practice)

Through Darkness to Light

by Kathy Nimmer

Heartland Community Church (RCA), Lafayette IN

As an elementary student, I began losing my vision. What started as a problem seeing the chalkboard ultimately yielded a diagnosis that meant large print and public school, large print and a blind school three hours from home, braille, use of a white cane, then near total blindness, over the course of sixteen years.

Each stage of visual decline brought grief. I mourned being just another kid. I mourned taking gymnastics classes. I mourned a certainty that I could do something of meaning in this world.

The retinal deterioration introduced me to depression, anorexia, and, most daunting of all, hopelessness. Every decline made me feel emptier, and while I tried to fill that emptiness with overachieving, I could never win enough to find any real value in myself.

In ninth grade, after proudly making it through an anorexic weekend only eating a half an orange, I found myself in the living room of a pastor to whom my parents delivered me for a day of hard-hitting, straight-talking, faith-driven counsel. That pastor planted a seed: my value was not in "doing" at all. He showed me that each of us has innate value in being a child of God. We can't do anything to increase that value, like winning or achieving or even seeing. I began to realize that we are each gifted with something no one else has, a combination of who we were created to be and what we've experienced in our journeys.

My life is full and rich these days: teaching sighted high school students, meeting with superintendents from all over the nation, chatting with other Teachers of the Year about our shared faith, speaking in front of enormous audiences, advocating for job opportunities for those with vision impairment. I am also reading my Bible on an audio device, following church happenings on Facebook with the help of a screen reader, learning braille piano music to play at Christmas Eve service, and falling deeply into worship through the beautiful songs sung by the praise team. Additionally, I am a substitute for sermon delivery, sharing with congregations I cannot see about what I can see daily in my life: God's guiding presence. There is something compelling for listeners about words of faith coming from a person whose every step literally requires faith. I am glad to be used by God in that way.

For me, my disability intersects with my faith in that I am grateful, truly grateful, to be blind, for it is through that darkness that I revel in the Light.

Themes

Winter 2017—Disability and spiritual practice. How does living with a disability shape our own spiritual practice? As people who belong—body and soul, in life and in death—to Jesus Christ, where do the rhythms of disability and of devotional life intersect? This issue features stories reflecting the spiritual practices of people with disabilities.

Spring 2017—Paid caregivers. Many people with disabilities receive supports from other people. If you hire and manage caregivers for your own support, receive support in a group home or other living situation, have a loved one who receives paid support, or if you are paid to give care to a person or persons with disabilities, please send us a note about your experiences by February 1, 2017.

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Teaming up with God and Others

by Rev. Ken Petty Jr.RCA minister, Alpha NJ

My life changed in 2007—how I think about myself, how interact with family, how I interact with other people (friends, pastors, church members, community members, strangers)—thanks to a diagnosis of early onset Parkinson's disease. Every part of my life was changed by the symptoms of Parkinson's disease or side effects of the medication that I must take, including how I did ministry, wrote and preached sermons, planned and led Bible studies, did counseling. Even my prayer and devotional life changed.

I have discovered that I need to pace myself physically and spirituality. If I do too much on Wednesday—like going to an ecumenical breakfast that ends at 11, then leading a Bible study until 12:30, then doing an hour of counseling—I am so drained physically that I am unable to move much that night and virtually all of Thursday. This physical exhaustion makes it practically impossible to read, let alone meditate upon God's Word, so physically I pace myself, which is not easy to do.

Pacing myself spiritually takes a team that consists of the Holy Spirit, my wife, my daughters, members of my Wednesday Bible study, and a couple pastor friends. Parkinson's has made it necessary for me to rely upon the people that God brings into my life and to lean on God more each day.

This wonderful team helps me physically by moving things and driving me places, for example, but also spiritually by encouraging me and praying for me.

I have many of the usual symptoms of Parkinson's as well the common side effects of the medications. These include cognitive issues (I can no longer debate or have in-depth discussions), dyskinesia (uncontrollable, involuntary muscle movement) and dystonia (involuntary muscle contractions), a slight stutter, and facial masking (facial muscles become immobilized, causing a blank expression), among others.

Yet God continues to speak to me, even when I fall asleep while writing sermons or lessons (I caught myself starting to doze off at least three times as I wrote this). I'm also learning to trust and lean on the people who love me, even as I lean on God more each day and seek to live out John the Baptist's teaching about Jesus in John 3:30 ("he must increase, but I must decrease").

A Life of Mystery and Faith

by Rev. Andrea Godwin-Stremler RCA chaplain, Fort Polk LA

Spiritual practice is in the very marrow of my disabled bones. Even in the bone that was grafted into my leg. When I was a small child, people would ask me if my cast was heavy. I had no idea. I couldn't remember ever being

without one. Similarly, I can't answer the question, where do disability and your devotional life intersect? I've never been without either one. Intertwined, they are one in my inmost being. I cannot remember a time in my life before I was aware of God's glory, Jesus' love, and prayers of the faithful.

Last year I met a cousin my age for the first time. She said, "I prayed for you with my family every night." During the first 12 years of my life, the prayers were focused on healing my leg. I was in plaster casts or wore leg braces continually. I used crutches and was in and out of a wheelchair. At age 12, I was finally able to put all of those aside and walk. The church rejoiced and praised God.

But I also became a visible reminder of the mystery of God, the part we don't like to see. My legs don't match. I have multiple surgery scars. I walk with a limp and with pain. The underlying disease remains alive and active in my body. It continues to create new physical brokenness, pain, disfigurement, and disability. It is a mystery full of unanswered questions. Failure to heal, even after prayer, is a mystery to God's people. And usually the faithful would prefer God only to be mysterious, not people or the circumstances around us.

In the quiet and at night, when alone, is when I struggle the most. I say the words of Psalm 139 as a personal confession of faith: "I am fearfully and wonderfully made." Yet as I live my life in daylight, in church and society, I struggle to celebrate this wonder. Like the psalmist, I cry out for understanding, strength, and relief.

The Bible contains many stories of healings. It is filled with admonition to "ask, and you will receive," and "approach the throne of grace with confidence, for he who promised is able." Yet, did Jesus heal everyone he encountered? What did the healings look like?

I had the blessing to minister to the community living on Molokai, Hawaii. The people I ate with, played cribbage with, and then worshiped with were living survivors of Hansen's disease, or leprosy. The bacteria that caused the disease was dead and the people fully cured. Yet the deformities, disabilities, and marks of the disease remained. As for the lepers healed by Jesus in the Bible, were their bodies completely restored to "normal," or was just the disease removed?

Living with disabilities shapes everything about me—my faith and spirituality, my relationships with others, and my daily living, both mundane and victorious. God's faithfulness indeed is great, as the hymn proclaims, but so is the mystery of God.

Trusting in God, Relying on Others

by Rev. Stacey Midge

First Reformed Church, Schenectady NY

When we speak of spiritual practice, we usually think of individual disciplines like prayer and Scripture study. One of the useful tools I have discovered and developed for myself is a rule of life—an intentional pattern of structures that provides a rhythm of life—that includes these and other personal actions. I have always been an independent person, and my ability to create and stick to individual spiritual disciplines is limited only by my attention span.

However, living with epilepsy has pushed my spiritual practice beyond individual disciplines. My seizures are controlled now, but when I have had breakthrough episodes, I have found myself terrifyingly dependent on other people. It's easy to say that I rely on God, but trusting other people to care for me and make decisions on my behalf when I am unconscious is considerably more challenging. Depending on others to help me with transportation and other post-seizure limitations is even more difficult. I hate to ask for help. I hate to be the one who needs. And yet, I believe that this is part of what the body of Christ exists to do: to care for each other and to fill the gap between each member's individual ability on their own, and their fully thriving potential as a member of the community of God.

In order to hold onto that principle when I need it most—when I must rely on others—my rule of life has had to stretch to include more communal disciplines that challenge me to depend on others in my daily rhythm. These are unusual spiritual practices, ones I suspect you

will not find in most books about the topic. One of the disciplines that I am still mastering is that, when someone asks if they can help, I let them. Instead of trying not to impose, or thinking I could do it better myself, I allow myself the gift of one less thing on my plate. Over time, it feels much less strange to simply ask for the help I need, as I learn that people really are willing most of the time. Another of my disciplines is intentional vulnerability. I participate in specific circles of people who mutually challenge each other to be authentic and open. In daily life, I try to be forthcoming with the people around me about my epilepsy, and what it means that I live with the possibility that I may have seizures again.

It is not easy for me to admit that I have limitations, but the spiritual practice of greater honesty has brought me a greater sense of trust for my faith community. Although this may not appear to be specifically "spiritual," relying on God's people has also made tangible my reliance on God, who reaches for me even when I am unconscious and unable to reach back, who knows my limits and yet makes it possible for me to thrive, who holds me in life and in death.

Becoming More Focused in Prayer

by Michèle GyselinckFirst CRC, Montreal QC

Because I was prone to auditory hallucinations (hearing voices) for many years, and because they were distracting me, I developed the habit of writing down my prayers. Writing them made it easier to keep track of what I'd already said and avoid repeating myself endlessly

It helps even if you don't hear voices. Last summer we had a prayer meeting during which my district elder asked God for help in keeping her focus when she prayed for the people in her charge. During a break in our prayer time, I suggested she write her prayers. When I last asked her how her prayer life was going, she said there was a huge improvement.

To keep my prayers together I buy a book with lined paper and dedicate it entirely to my prayers. Since I've been doing that for years, I also put a sticker on the book cover indicating which part of my life the book covers.

Some years ago, I went through a dark period in my life when I was deceived by the devil. I've been a Christian since 1977, so it was not demon possession. A former pastor told me that where the Holy Spirit is, the devil cannot control. But I was being deceived. At that time I was writing my prayers in books at the kitchen table. Because I had been traumatized by this experience of deception, I made two changes. I wrote my prayers in notebooks instead and sat on my couch in the living room. These changes helped me make a clean psychological

break. As time passed and the trauma faded, I went back to using books, but I still eschew the kitchen table.

I have been praying in writing on and off through the years, and I keep coming back to it. Whenever I try to pray orally, I find that I am all over the place; whereas, when I write prayers I can go back and see what I'd already mentioned and move on. I find this practice helpful, even when there are no voices to distract me.

We often have a lot of things that pop into our minds when we sit down to pray. If you write down your prayers, your mind is less likely to wander. You can also write a list of things to address in your prayer, though you may find that you end up spending most of your prayer time making lists instead of praying. My written prayers are not lists of items I want to pray about. They are prayers in writing. This is how my disability has impacted my spiritual life.

Editor's Note

Growth through Disability

Christians believe that our faith in God is a gift of the Holy Spirit, not something we create on our own. Individually, however, we have a part to play in nurturing and deepening our faith by devoting ourselves to practices such as Bible study, prayer, worship, and service. Some practices can be more beneficial than others at various

stages of life—as people grow and change, so might their spiritual practices.

The articles in this issue attempt to describe spiritual practices of individuals based on their disability. The idea for this theme came from a 2015 Christian Century article by Janice Jean Springer, "Illness as Hermitage: How Parkinson's Became My Spiritual Practice."

Our authors have written from a range of perspectives: epilepsy, mental illness, Parkinson's, blindness, multiple disabilities; some have always lived with their disability, and for others disability came later in life. Though my own disability has been with me since birth, I resonated with aspects of every writer's experience. I hope you will as well, disability or not.

—Terry DeYoung

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