Breaking Barriers

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Summer 2014 (Chronic Pain)

Chronic Pain?

by Laurie Baron

Hope Church (RCA), Holland MI

After I'd been out of commission for a few months, my pastor made a passing reference to "these chronic conditions." I corrected him—my condition wasn't chronic, it was just slow to abate. Now, five years on, I still don't know what to call my dis-ease and wonder whether I will ever feel "normal" again. But my dictionary defines chronic as "persisting for a long time," and there's no denying it's been a long time.

If I resist the word "chronic," I hesitate to claim "pain" as the problem. I've told doctors often that I don't really have pain. Rather, various discomforts and malfunctions, sometimes manageable, sometimes incapacitating, have wreaked havoc with my life and expectations.

So the doctors turn their tests and skills toward finding an answer for me, but so far solutions have been partial at best. In fact, I look quite healthy. I respond to this clearly good news in a variety of ways: I have been angry, cynical about medical practitioners, depressed, panicky, convinced I am faithless, convinced I am losing my mind, convinced I am an emotional cripple, or a few of these at once. Always, I carry the weight of my paradoxical reality.

Slowly, I am coming to learn that this struggle is itself a kind of chronic pain. If I can’t name my suffering, how can I control it? How can others understand it? How do I care for myself, and how can others care for me? Can I still be of use to anyone? The easiest thing is to back away from the questions, the fear, and the confusion that is alive in me and obvious in the faces around me.

During the darkest time, I began to notice some faint lights glimmering. A few people kept popping up in my inbox—even mailbox!—not close friends or designated caretakers but people from my church who noticed my absence and sent greetings. My pastors and a few confidants stayed present. They believed me and continue to respect my experience even on the days when I find it difficult to do so. They honor and welcome my gifts and accept unquestioningly the extent to which I feel able to serve. Their openness has helped me swim against the tide of isolation and toward life and wholeness.

An old intercessory prayer may resonate for others as it does for me: May God’s Spirit—and God’s people—be present “with all who suffer with whatever their suffering may be called.”

Themes

Summer 2014—Chronic pain. In this issue we explore ways chronic pain affects individuals and how churches might respond.

Fall 2014—Public advocacy. Advocating for people with disabilities within your church likely is different from advocacy beyond church walls. By August 1, please send us a note describing how you or others have moved outside the church to act on behalf of people with disabilities.

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My Constant Companion

by Andrea Godwin-Stremler

RCA minister in Fort Belvoir VA

Life with chronic pain is filled with blessings and curses. I am blessed with a full and busy life, serving as a minister of Word and sacrament and licensed therapist. I run my home as wife, mom, and grandmother. I am the full-time caretaker for my 6-year-old granddaughter.

Yet, I am challenged in this full and busy life with pain. Pain is my constant companion 24 hours a day, 7 days a week. I go to sleep in pain. As I prepare for sleep, I ask, “Do I need to take pain medication, or can I relax and go to sleep without it and feel a little better by resting?” Throughout the night I wake with pain in one part of my body and change positions, seeking (temporary) relief until waking again.

Getting started is a painful process, but so is remaining in bed. So I begin the process of moving—a painful process that gets less painful if I can just get going. Throughout each day, I continually balance between standing, sitting, and moving. If I do any one of them too long, my pain increases.

Some days the pain is “off the charts,” making me cranky and short with those I love and work with. My body spends so much energy fighting the pain that sometimes I’m exhausted before finishing my to-do list.

Pain is a constant, left over from 32 surgeries and multiple tumors in my body—and a new pain companion has joined in, arthritis. Short of God’s miraculous healing, pain will always be present for me.

Psalm 139 is my life passage, and God’s predestined will for my life gives me peace and comfort. Daily I pray that his glory may show through me, and it does, even though the pain remains.

Adjusting to Chronic Pain

by Jan Ortiz

Bella Vista Church (CRC), Rockford MI

In 1973, I was diagnosed with rheumatoid arthritis (RA) and—unbeknownst to me—fibromyalgia, two chronic diseases with no known cure. I had guessed that the RA diagnosis was coming because I had been having symptoms for the previous nine months. Fibromyalgia was unknown territory and did not even have a name until 1981.

In those early days, there were few medicines available to treat RA, which attacked my hands and feet first. My feet and ankles hurt so bad that if I'd been sitting, I'd have to stand for several minutes, sit down, and stand again before I was able to walk. This was particularly trying in church, where I felt people were looking and judging, though I don't know this to be so.

Because I could not pick up my 18-month old son, Jonathan, with my hands, he had to adapt to being picked up on my forearms. He made the change with no fuss—what a trooper. Within the first four years, my wrists fused. By the time the sharp, stabbing pain subsided, I was left with a range of motion in my wrists that is the same as what I have today—not much.

Mostly, I remember the intense pain from trying to spread soft butter on bread; fused wrists also change the way you hold things, pick up things, open doors, etc. The debilitating pain of the fibromyalgia exhausted me, and as a result I spent my days lying on the couch dozing while my son played with his toys nearby. I thank God that Jonathan never got into anything he wasn't supposed to.

People have said hurtful things. I have tried to let those go, but once words have been uttered they can't be taken back. I don't know why God blessed me with these diseases; he has been silent when I have asked. I am sure I have not lived my spiritual life to the fullest potential, but I still expect to have all my questions answered when I get to heaven.

The Routine of Chronic Suffering

by Judyth Nydam

Cadillac CRC, Cadillac MI

For the first few months, when people saw me struggling with my pain, it startled them, eliciting compassion and deeds of caring. But when months turned into years, my pain became routine for them. Intellectually they acknowledged that nothing in my health had changed because I always used a cane or a walker and never participated in social events that required mobility.

The person experiencing chronic pain responds quite differently to her own suffering. Neither the pain nor the problems it creates ever feels routine. Pain always hurts, always needs management, always incapacitates. Each day presents the challenge of attempting to achieve at least some time of less pain (not no pain, just less) in order to shop, clean, socialize a little, or have a little fun.

Chronic pain sufferers must “cocoon” what’s left of their lives to retain their sanity and minimize the expectations of others. They become part of the routine landscape of other people’s lives, and they seldom get a “wow” of caring. It’s not that people don’t care; it’s that people forget to care.

So what’s to be done? If spontaneous encounters of caring dwindle because caring people have become desensitized to the need, then, like the reminder cards we get from our dentist or veterinarian to provide care for us or our pets, we should "routinize" the caring that chronic sufferers need. Deacons or other caring groups and individuals simply need to put suffering people on a schedule of receiving care. As faithfully as we pay our mortgage, we should automatically "pay out" our compassion to needy or suffering people as part of a routine ministry, and make sure to follow through. As devastating as it is to the suffering person to be ignored, it is just as demoralizing to receive promises of help that are never fulfilled.

When my husband served as pastor of a church, he had a list of the people on whom he called regularly. Calling on them was as routine as getting an oil change for the car. But he discovered that routine acts of caring always produced the "wow" of genuine caring.

People who know daily pain and suffering should not be taken for granted. We provide others with a "wow" look into the grace of God who sustains us in our life of pain. Please don't forget us—and don't allow us just to blend into your people landscape.

Medicine and Lots of Support Help

by Cor Visser

CRC regional disability advocate, Classis Hamilton

My dictionary says that chronic pain is “constant physical suffering or distress due to injury, illness, etc.” That’s me! In my case, chronic pain is my body telling me something is wrong and to stop doing what I am doing, but that’s not always possible.

When I was young, I thought I could do everything. I tried to work harder and lift more than anyone else. I sometimes overdid it. As I grew older my body started to show signs of the sins of my past. A few pills, a back massage, or a few days off work usually solved the problem. Over the years I had to resort to anti-inflammatory drugs and painkillers to deal with the nagging pain. Now, at age 66, I use a pain patch that is a rapid-response, short-acting narcotic similar to morphine. Like most drugs there are side effects such as addiction, loss of appetite, weight loss, mood swings, fatigue, and high blood pressure.

Presently I have severe degenerative disc disease, signs of stenosis, arthritis, and bone spurs. People ask, “How do you cope with your pain?” I have a lot of good days (thanks to medicine) that I cherish, and on the other days I lean on my heavenly Father. When I Cfeel sorry for myself, I look at people worse off than I and realize how blessed I am.

My main support is my wife Diane. She knows the right things to say and do to get me back on the right path physically and emotionally. She makes sure I take my meds on time, that I get the proper rest, and even tells me to smarten up when needed and to get on with life. My children are also a big support. They know Dad can't do certain things anymore and help out, and they know when to let me disappear to the bedroom to get some rest if I am having a bad day. Our friends are there for us with their help and prayers. I can lean on Pastor Martin for regular visits that include times of prayer. My heavenly Father is my biggest supporter. Maybe this thorn in my flesh brings me closer to him. I look forward to the time when I will no longer have this chronic pain. Maranatha! Come soon, Lord Jesus!

When Pain Takes Over

by Lisa Tice

RCA military chaplain, Andrews Air Force Base MD

When I first met my husband, Jonathan, I had no idea how much he suffered. He talked about surgery that he had as a child, but nothing appeared unusual. He had a wonderful sense of humor, a sense of adventure, and a depth of theological knowledge that astounded me. I had no idea how much he suffered, because he kept it hidden.

When we dated, he mentioned his pain but never dwelt on it. Occasionally he wasn't feeling up to going out, but those times were rare. We were like most newlyweds, completely in love and happy. I eventually started my military chaplaincy career and he became a specialized interim minister. We traveled and enjoyed life together.

But with each move, his health deteriorated and his pain increased. Another round of surgery and a life-threatening staph infection made things worse. We sought out a variety of medical specialists to find a way to alleviate the pain, but there is no easy fix. Now, we only seek to find a way to bring the pain down to an acceptable level.

Chronic pain has shaped our lives and it has isolated us. We don't get out much and we don't travel. I feel helpless as I watch Jonathan suffer. I covet the moments when he makes me laugh or shares his keen insight on the world. More often, I cry out of frustration with insurance, or I stress over balancing work, caring for our son, and trying to improve my culinary skills. Every day I pray for an end to his pain. I dream of his finding relief and of us enjoying a happy retirement, but I know that it is only a dream.

If someone were to ask me if I still would have married him—knowing how much he suffered then and would suffer now—I would answer yes. Every moment of joy that we have shared is a ray of light that helps me forget the darkness of chronic pain.

A Hurtful Label

by Joe Schaafsma

Bethel CRC, Dunnville ON

A kidney stone condition since age 21 has brought much suffering, and not just for me. Often the effects of chronic pain have inflicted a negative attitude towards my wife Margaret, our family, friends, and towards God. Bitterness is a poison!

I have difficulty getting and keeping a job. Even though I want to work and am capable of working in many capacities to receive an income to support my family, I have been labeled “disabled,” which is hurtful. This pain is hidden from society, and it results in guilt and shame. Physical pain is not just physical, but also emotional and spiritual.

Few people understand that it’s all encompassing. We are blessed with good medical care and medication to control the physical pain, but chronic pain always demands attention.

Editor’s Note
Start with Compassion

This spring, in the days prior to and especially following knee-replacement surgery, I was asked several times a day, “How would you rate your pain on a scale of 1-10?” Frequently, pained by uncertainty, I would respond with a mocking precision that puzzled the questioner. “3.63,” I’d say confidently, pausing for effect, “but I’ll leave it to you round off that number for your charting.”

I was having fun, mostly, but if a simple question to measure pain at a given moment is a challenge for some of us, imagine the chore of defining, tracing, or pinpointing something evasive, mysterious, and misunderstood like chronic pain.

Generally pain is a protective sensation, an alarm essential for our survival. But sometimes pain seems to go haywire as systems malfunction, sending false alarms that torment people's lives.

Although an estimated 100 million North Americans live with chronic pain, there's no telling who the victims of chronic pain will be. Chronic pain may be traced to something like arthritis, fibromyalgia, or neuropathy, but in many instances the cause is not identifiable, diagnosable, or logical. For example, do you know anyone who experiences phantom pain associated with an amputated limb?

If doctors and their patients are stumped by chronic pain, how can we in the church possibly help? We can begin by showing compassion—listening, trying to understand, praying for one another, offering assistance with practical tasks. As John Cook cautions in his helpful resource, A Compassionate Journey: Coming alongside People with Disabilities or Chronic Illnesses, avoid giving advice or seeking solutions. "Ultimately," writes Cook, who lives with chronic fatigue syndrome, "trying to 'fix' things will lead us away from genuine caring."

—Terry A. DeYoung

More Online

Due to space limitations in the print newsletter, more complete versions of these Breaking Barriers articles, plus a letter to the editor, can be found online (www.crcna.org/disability and www.rca.org/disability).

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