

Living on the Edges

by Charlotte Caron and
Gail Christy

Cet article décrit l'expérience et les croyances spirituelles de deux femmes qui sont handicapées et qui souffrent de

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maladies chroniques et l'impact de cette spiritualité sur leurs handicaps et maladies chroniques.

Charlotte Caron and Gail Christy are members of the Barbwire Collective, a group of nine women who, over the past three years, have been writing about living with disabilities and chronic illnesses and the spiritual resources that help us and that emerge out of our experiences. Gail has lived with mobility impairment since birth and reflects on how faith has been a sustaining dimension of her life. Charlotte lives with chronic illness. She reflects on how theologies of the Christian church have influenced her life. Both are members of Christian churches and Charlotte is also active in feminist spirituality groups. The article is written in two voices to show our different experiences and perspectives.

Some effects of disability/chronic illness on how we think about/experience spirituality

Gail: My disability dates from the time of my birth so my experience of the world was never typical. I have the gift of being sensitive to my environment. This meant that from a young age, I experienced both the

goodness and unkindness of people. When I think of unkindness, I recall laughter and pointing fingers and snowballs thrown at me when I could not move out of their path. But this same awareness that caused me to notice derisive laughter, also enabled me to remember and treasure the acts of kindness that have been part of my journey. I knew, deep within me (even at the age of six) that God was ministering to me

through people.

Charlotte: Unkindness and the fact that people do not always think about the consequences of their words and actions angers me. But being part of a liberal Christian church has meant that I learned from a young age to be nice rather than to be angry. Most white, middle-class North American women are taught to be passive instead of angry. The risks are very high for women with chronic illnesses and disabilities to express their anger, especially those dependent on attendants, care givers, families, and friends. Isolation is a constant possibility. Thus anger is often repressed, or turned in on oneself. Anger can, however, be the motivator to get creative power moving toward changes so that we all have access to the resources we need to participate freely and fully in the community.

Gail: Participation in community is really important to me. I think this was due to my disability and to the community that surrounded me. As a youngster, beginning at the age of five, I spent considerable time in hospital and I attended a special school. These are rarely regarded as positive events. But I knew and experienced God's love through the staff of these institutions. The other kids were wonderful friends and we helped each

other manage our problems. For example, the boy who was blind chummed with the child who was deaf and the girl in the wheelchair was often seen with a girl who was ambulatory but whose speech was impaired. We were a grand community full of life and joy!

Charlotte: Living with chronic illness has pushed me to a new understanding of diversity. The range of disabilities that people experience and the kinds of impairments created by living with chronic illnesses mean that we have to work together if we are all going to have our rightful place in the world.

Disability is a socially constructed phenomenon. It is constructed to create hierarchies—to keep a powerful few in control of the resources that are needed by others for basic survival and for full and free life. It is based on keeping some people invisible and powerless. Thus those desiring power seek homogeneity—seek to be as much like those in power as possible. Women with chronic illnesses and disabilities cannot succeed in such a system. The norm has to be diversity and acceptance of difference for us to belong. I believe that what makes communities spiritual is the capacity to integrate diverse realities, to connect people to each other, and to seek justice and safety for those who hold least power in society.

For diversity to be a reality, each person must be able to communicate her/his reality. People have been taught that respect is not asking about disabilities. This habit of ignoring disabilities denies how hard our lives are and inhibits dialogue about how these attitudes and practices affect us. It is especially important for those of us who live with the uncertainties and unpredictability of chronic illness to be able to make some choices. To do that we need voice—we need to be able to speak about our lives as

they really are, the struggles and frustrations of living in a society that disables us, and the wisdom we gain from viewing the world through this particular lens.

Gail: I used to think the process of being spiritual was closed to me because I experienced too much physical pain. This pain means I am not able to sit for long lengths of time in contemplation nor can I concentrate for too long because the discomfort of my body impinges on my concentration. Now I know that my encounters with God do not have to be lengthy to be meaningful.

I think that the emphasis on the "otherworldliness" of spirituality has done a disservice to those who live with disability and chronic illness. Pain is often a major reality of our lives. Yet I was once advised to "surrender all pain to the universe."

This may be a wonderful idea but for people living with chronic illness or disability, it denies the reality of our world and sends messages that pain is not really all *that* terrible—just a momentary thing. For many of us, it is not like that. Rather, pain is like a heart-beat, always there. The plus side of living with this pain is that my endurance skills have been superbly honed.

Charlotte: Part of our spiritual strength is learning from our pain. All of us know pain—some physical and mental pain, some the pain of loss, some the pain of rejection, humiliation, and discrimination, some the pain of despair. Ways to live with pain are spiritual gifts much needed by our world. Spirituality is one of the ways of seeking hope and courage in the midst of pain and despair.

Certain strains of Christian theology have suggested that God gives pain and suffering to provide meaning and that we simply must search for that meaning. Some New Age philosophies stress that we choose

our illnesses and disabilities because we have something to work out in this life. Both of these formulas blame the victim. Susan Wendell is much more helpful when she states,

having experienced a crisis of meaning in my body, I can no longer assume that even powerful bodily experiences are psychologically or spiritually meaningful.... With chronic pain, I must remind myself over and over again that pain is meaningless...." (120)

I find it constructive to believe that there is no inherent meaning in suffering, chronic pain, chronic illness, or conditions of the body that are disabling. They simply exist as part of the diversity of creation. Not everything has meaning.

We need endurance as a spiritual resource. Eleanor Haney says that endurance shows that the human spirit is tough. It enables people to lead complex lives in incredibly difficult conditions. It is her contention that theological and ethical literature often ignores endurance focussing on

Gail: The concept of "dwelling" is important to me. Maria Harris in her book, *Dance of the Spirit*, suggests that there are four places where women can dwell at different times in their lives: desert, garden, city, and home.

I have moved among these dwelling places of spirituality and my disability influences these places. It can influence the length of my stay, and the depth of my feelings. Harris describes the desert as a "place of sorrow, emptiness, and ending" (93). I know these feelings well because the world has isolated me in my difference. I sorrow a lot because sometimes to live with disability is "cruel and unusual punishment" in a world where movement for others is easy and effortless. The desert is not an easy place to be but my disability had led me to know it well. Sometimes it feels like a place of endings and no beginnings.

Harris describes the dwelling place of the city as symbolic of reaching out to others. Relationship is its important focus. The assumption is that we actively do the reaching out, that we initiate and sustain relationships. As

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what we should do in situations rather than on the question "how much longer can I hold on doing what I have to do?" She suggests that hanging on shows "a self exercising responsibility, a self of often tremendous moral courage" (15).

Endurance is a spiritual and moral resource for the boring, exhausting, and uncertain times.

someone living with a disability, I have come to welcome initiatives, and first learn to "be" in relationship, rather than always to "do." My disability does not exclude me from the spirituality of the city dwelling. I just have to acknowledge my value as someone through whom others can also know their dwelling in the city. My being open to people who want

to assist me answers a need for both of us. Again we reflect on the benefits of mutuality—something that living with a disability teaches well.

My garden times grow out of my ability to be nurtured by my physical environment, even though that environment may seem pretty limited, for example, to the chair I am sitting in. When I was encased in total body casts, I honed these garden time skills. From my bed, I learned to appreciate skies of different hues and tree tops whose dress changed with the seasons. This legacy serves me well now. I cannot do lengthy walks but I can go in my imagination, or I can focus on something close to where I sit—a leaf or a scurrying ant. Anything in creation reminds me of God. Living with a disability has made me aware of the sacred in the midst of life. I think, too, because I have had to be sedentary, I am more able simply to be. I am content to dwell where I am.

How has spirituality affected how we think about/experience disability/chronic illness?

Gail: When I first thought about this question, I became quite annoyed that I have a mobility impairment. The practice of spirituality had always been associated, in my mind, with gentle, effortless, movement. I cannot move that way. Thus I thought that I was closed off from the “normal” expressions of spirituality. I once left a women’s spirituality group because I could not tolerate the isolation I felt when they moved about in graceful dancing circles. However, reading and reflection have taught me that there is much more to spirituality than moving your feet and raising your arms. You actually can be spiritual while sitting still.

The fact that one can experience God though the gift of our senses has made me grateful to God for the care that is lavished upon us. I may have a disability, but that does not limit my access to God, does not limit my spirituality. My deep awareness of God, through the agency of other people, nature, and hard learnings

that have enriched my soul, has led me to regard my disability (at least at times) with thanksgiving. I have learned deep truths by witnessing both the goodness and unkindness of people. I have learned lessons about acceptance and rejection. And I have learned that no matter what, I am a beloved child of God.

Charlotte: Christianity asserts all people are equal and are made in the image of God. But I think it is hard for women with chronic illnesses to keep strong self-esteem, to know we are loved and loveable. Frequently we have experienced situations in which we are demeaned and humiliated. If our needs vary from day to day, we are seen as unreliable. If our disabilities or illnesses are not clearly visible, we are seen as imposters.

Yet “all people” includes those with disabilities and chronic illnesses. Whatever God/dess is like, we are a part of that. To live in the image of God/dess means self respect, acceptance, and using our unique gifts creatively and courageously in this world.

Many people suggest God is a source of comfort in rough times. I personally have not often found the comfort of God. More often I have known the presence of God when I needed the courage to do/speak for right when injustice/discrimination were present. When we have a disability or chronic illness, we have the mixed advantage of living on the edges—never quite fitting, but also not caught into the contradictions of privilege of the powerful. The edges do not always provide us with the safety we need, nor are our survival needs always well met. Yet from the edges we can name injustice and stand in solidarity with others who do not have privilege and power in society. From the edges we can question everything and express the doubts and outrage embodied in our faith. We can speak out for the rights of those who are oppressed and disadvantaged by society, knowing that the presence of God is in the midst of people’s suffering and that God’s bias is for the oppressed. All need to participate if the community is to be whole.

The spiritual for us

As women with disabilities and chronic illnesses, we need to tell our stories honestly, to be accompanied by people who love us, to dwell in just and compassionate communities of mutuality where we can participate fully and freely, where endurance is valued, and where we offer wisdom on how to live with suffering and pain. Our spiritual lives are strong when we believe ourselves to be made in the Divine image, when we see ourselves mirrored in the Holy, and accept ourselves as loved unconditionally by that Creative Spirit.

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Gail Christy, a member of the Order of Ministry of the United Church of Canada, has served pastorates in Saskatchewan and Ontario. She has written for children about living with the challenges of disability. She thoroughly understands the dynamics of “living on the edge” and continues to do so as she carries out her ministry on her current pastoral charge in eastern Ontario, counselling at a community college and as a chaplain at Elisabeth Bruyere Health Centre in Ottawa.

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