

Being with What Is Teaching Meditation to People with Chronic Pain and Disabilities

by Naomi Weissman

The label “disabled” is so frightening. Out of fear I separate my longing for connection to other disabled people from the terror of what I might become. For more than 10 years I’ve been trying to pretend I’m not disabled. After all, I look normal—I can walk, talk, sit, stand. Hardly any of my friends are disabled. I have no wheelchair, no attendants. I’m not like the others in the disabled community. I walk along like everybody else. But it’s painful to walk, painful to sit, often painful to lie down. Back pain awakens me at night and greets me in the morning. After various doctors, tests, procedures, and contradictory theories I still have a lot of pain and it doesn’t go away.

I stopped working almost six years ago when the pain in my body was simply too intense for me to continue the life I had. I hoped that by slowing down, getting rid of the pressures of work, spending time doing my art, working with various healers, it would all change. I’d be cured. Or I’d wake up one morning and the pain miraculously would be gone. Or someone would invent a painkiller that keeps working and has no side effects. Western doctors call what I have “degenerative disc disease,” but opinions are all over the map when it comes to what’s actually causing the pain, and there are even more opinions about what, if anything, can be done. At times I try new treatments, new doctors; other times, I tire of being a patient and I work on my own with an amalgam of exercises I’ve put together from yoga teachers, physical therapists, chiropractors. I don’t notice that they help much, but people say I’d be in worse pain if I did nothing.

Since about 1980 I’ve been meditating in the vipassana tradition. I’m the third kind of meditator the Buddha spoke of—one for whom it’s hard in the beginning, hard in the middle, hard at the end. My faith wavers, yet I go on week long retreats and try to be with my body, pain and all. It’s easy to fall into resentment, self-pity, comparing mind, and especially aversion to the pain. Even so, I invariably leave retreats feeling deeply connected to the practice and to a part of myself I barely know. For me it’s another way of looking at things, experiencing life at a level of ease and acceptance so different from my conditioning. I continue to find the Buddha’s teachings a practical and meaningful system of dealing with suffering, my own and others’. So I continue to practice. It’s often a struggle, but then, I’m a struggler.

A year and a half ago I signed up for a group at the Berkeley Zen Center called Suffering and Delight, run by Darlene Cohen, a Zen priest with rheumatoid arthritis. The group was to meet once a month and explore how one could have a joyful life living with pain and disability. As I entered the community room for the first time and looked about, I was flooded with an almost overwhelming level of compassion. Two people were in wheelchairs while the others lay about on the floor with a varied array of cushions and pads, following Darlene’s dictum of getting as comfortable as possible. People told their

stories and I listened with a mixture of horror, fascination, sadness, and care. One person had muscular dystrophy, another could not speak without great pain, and others had varying degrees of disability, all much worse than mine, or so I judged.

By the end of that first afternoon I had begun to comprehend the tremendous courage of the people around me in simply being willing to live their lives. My own trials seemed trivial by comparison, but on some level I understood that I was, after all, part of the group and as such, deserved as much compassion as I felt for the others. It was a revelation that marked the beginning of an ongoing question: how to hold my pain more compassionately and in a way that allowed for not only suffering but delight as well. Darlene's message was that we could see pain as just one aspect of our lives, and that we could also cultivate moments of pleasure and joy. We could move toward resting in what Trungpa Rinpoche called "basic goodness."

Our ongoing assignment was to meditate for 30 minutes, five times a week. During the year and a half that the group met, we practiced Zen, vipassana, and body awareness meditations. To be honest, I often didn't do the whole 30 minutes—it was just too much to be with my pained body for that long. I did what I could.

Each month's session had a theme that Darlene spoke to, and we then worked with it on our own during the month. One theme was "connecting to our pleasure." During the month we were to track one pleasant experience each day, noting when we were aware of it, how the body felt during it, and whether the experience was something we had intentionally brought about or whether it was a matter of noticing something we were already doing. Another time we worked with anger, spending the month noticing and observing our anger, watching it change into something else. I watched my attachment to anger and my wish that it would change. And I saw that it could change in a heartbeat.

Sometimes I found myself angry at Darlene for showing by example that it is possible to both allow the pain and cultivate joy. I was forced to see my "this is too hard," story for what it was—my heart closing down to the pain—and to move beyond it if I could, and try to be kind when I couldn't.

Several months after Darlene's group started, Clay Taylor, another group member who had become a good friend, suggested that the two of us teach a weekly class in meditation for people living with pain and disability. Darlene's group had motivated me to want to help others despite, or perhaps because of, my pain. Between the group and my vipassana practice, I had learned something about meditating with chronic pain, and I felt a need to share my understanding and experience with others living with pain and disabilities. Clay is a real get-the-job-done kind of guy, and together we planned our class. Wednesday mornings we met on our adjoining mats on my living room floor and discussed our lives, our disabilities, the dharma, and what we might be able to offer. These meetings with Clay became a high point of my week, engendering more energy as we went along—reading, talking, and finding useful material, creating a six-week class that dealt with body, mind, and spirit. Clay was a member of the Berkeley Zen Center,

but he was interested in exploring the vipassana tradition. Together we found relevant readings from Buddhist teachers such as Joseph Goldstein, Jack Kornfield, Pema Chödrön, and Trungpa Rinpoche. One day when I voiced my concern about not knowing enough, Clay replied, “Whatever we give them will be better than nothing.” I return to that mantra in moments of uncertainty.

We created a flyer and Clay located space for our group at the Center for Independent Living in Berkeley. He interviewed people who were interested, we set a time, and we began our class. On Mondays, the day before the group met, I would experience great anxiety. Given the pain I was in, it simply didn’t seem possible to lead a group the next day. I wanted to lie in bed and read or space out watching television. But when Tuesday came and I showed up, the resistance somehow melted away in front of the group. The pain was there but no longer in the foreground of my consciousness.

Attendance was low, but that didn’t seem to matter except perhaps to my ego. The class went well. People were visibly pleased to be in a group addressing their issues from the point of view of Buddhist meditation practices rather than the viewpoint of psychology, although at times the distinction got blurred. It was, too, a place where people could discuss what was really going on in their minds and bodies and be heard and supported in facing the challenges of their lives.

J. came to the group with chronic pain and agitation from a hip replacement gone awry. For a long time she was convinced that she wasn’t doing the meditation right; it wasn’t the peaceful, blissed-out experience she wanted or thought she should be having. One day she said to me in amazement, “You’ve been meditating for 20 years and look how anxious you are!” We laughed. It was true. At that moment I think she saw that meditation offered her permission to be just as she was. At the end of the class, she exclaimed, “I’m allowed to have thoughts!”

After the first six-week session, Clay moved to Colorado and it felt too difficult to continue on my own. I had relied on his support, and I felt inadequate to be the leader without him. I wasn’t the person I had been 20 years ago. I felt diminished by the pain. And I could easily slide into my “bad Buddhist” story—how I don’t practice enough, am not loving enough, don’t do right speech very well... It was a challenge to pay attention to the part of me that had a deep appreciation of meditation practice, and to believe that I could use my own experience with chronic pain to be of service to others.

A strong motivation to continue was that the group members felt it was important for us to do so. And it was important to me, too. My career as a photographer was pretty much on hold. I spent a good part of my day trying to get out of pain and watching with despair its persistent reappearance hours or moments later. Routine maintenance chores became the focus of my days. Many of my favorite entertainments, such as going to the movies or out to dinner with friends, often caused more physical pain than they were worth. If my life was reduced to basics, I wanted to strengthen my connection to Buddhist practice so that I could stop trudging through my days in a miasma of exhaustion and anger. I needed to be doing something in the world again in order to move

beyond my own pain and fear. Teaching seemed a perfect way of helping others and challenging myself to go forward.

So I started the group up again. We now have eight members, and we meet at the Berkeley Zen Center, a space which lends a sense of sacredness to our purpose. With the group's approval I invited a good friend and fellow vipassana meditator, Ina Evans, to cofacilitate the group, though she is not disabled. Aside from Clay I knew no disabled meditators, and I figured that Ina had suffered in other ways in her life to make her eligible. Perhaps we all have.

Ina has been a good balance to my melancholic, Eeyore-like tendencies. While I want to dwell on the hindrances, she wants to speak of generosity and compassion. And having been friends for some 25 years, we're comfortable working together.

Ina leads a short lovingkindness meditation at the start and end of each group. At each meeting we discuss a reading and relate it to our practice. Last month we read a short piece called "The Story-telling Mind" by Thanissaro Bhikkhu, a Theravada monk who speaks of how we might learn to relate to our stories in ways that do not cause suffering. People told their stories, some about death and disease and incapacity. Could we confront these very difficult life situations with more compassion? Could we remove the self-contempt from the tales we use to define ourselves? Ina and I work hard to find relevant readings, and it's gratifying to see that people deeply connect to them.

I sometimes give a short talk based on the theme of the week, and Ina comments thoughtfully and humorously. Recently I spoke on "Being with What Is." Knowing I'm going to give a talk makes me more thoughtful during the week, as I relate my experiences to the subject at hand. Often I lead guided meditations—perhaps a body scan, a visualization of some sort, or a meditation on healing the wars inside us—I sometimes feel as though I'm watering a garden of thirsty plants.

At the end of our meetings we hold hands and send messages of well-being to each other and all beings. This and the group experience itself has created a powerful sense of heart-connectedness among us.

I have been moved to see group members awaken to the dharma and apply it to the bodies and minds we were born into. I talked with them in preparation for this article. Here are some of their comments:

L., a woman in a wheelchair with a progressive retrovirus that causes symptoms similar to multiple sclerosis, says:

All of the things meditation teaches me about living are directly counter to what I was brought up to believe. I feel as if, after all those years of therapy, I'm now involved in a substantial challenge to my stories, a real shift in consciousness. Being in a very tolerant community allows and facilitates that shift.

In the past I was so attached to results, and because of my physical condition, results were often meager. Now I can practice giving more credit to what I am able to do, appreciating what's there, whatever feeling or movement I do have in my legs.

M. has been blind since birth and has diabetes and other serious health issues. She says:

I'm an anxiety-ridden, worrying Westerner. So much of what I think of as physical healing has meant going to someone to fix it. The old "fix it for me" attitude is being replaced by a calming sense that on a deep level, I'm in charge of my own healing. I love the hand-holding lovingkindness we do at the end of each group. It grounds me and helps me feel more connected to myself. Not being able to see others can be very disconnecting, and this is a good antidote. Focusing on my heart has helped me connect to myself. It reduces the pain and fear, which in turn helps my healing.

B. is M.'s partner. He makes it possible for her to get to the group with relative ease, and at present he's our token male. He says:

I always used to think of myself as a compassionate person but I've found, getting older, it's easy to become more bitter. I often see myself as a nonsocial, isolated person and I find the group energy is a way out of that isolation. The Buddhist practice has helped me step back from myself, and not stay attached to my stories. It gives me a different perspective.

We're completing our third six-week series. The pain in my body is intense these days, but my sense of being useful to others has grown. I worry that my pain will be too debilitating for me to continue teaching, or that I'll have nothing to say. There's a long list of reasons why I can't do it. But each week we hold the group, and it works. Right now planning and running the group is the most significant thing I'm doing, and that knowledge is deeply empowering. It's a privilege to be working with people who, in spite of extremely difficult physical circumstances, manage to show up for the group and are touched by our teaching. This work deepens my own connection to myself, to the group, and to the dharma.

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