

Widening Our Circle: Being an Ally to People with Chronic Illnesses

By Diana Lion

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Very few people see me spontaneously any more. I am seldom out in public, due to invisible symptoms: debilitating fatigue, severe chemical sensitivities, migraines, and a tendency towards fainting. I am aware that each of my days has only a few precious teaspoons of energy, so I must choose wisely how to use them. This means clarifying priorities around emails, phone calls, tasks, and visits. It's excellent discipline. I am now accustomed to missing out on many things I used to do. But sometimes I need to work hard to respond compassionately when people have strong reactions to the few visible signs of my illness.

"Hey you! You scare me." a man yelled at me while I was on a rare outing to a farmer's market in Berkeley. I was wearing my painter's respirator which created a bizarre separation between us. I could see him, but he could not see my face clearly. I stood there and breathed, my arms filled with colorful veggies and roses, my heart pounding. Then he yelled it again. This time he laughed, a bit uncertainly, because I was rooted, and standing strong. I watched my mind, while he waited. After a moment of anger I felt choking sadness, and then hurt, because I didn't want to look like a monster. I'd almost made it through this venture out to the farmer's market without hearing any taunts. As I calmed down I realized that perhaps he *was* scared. He looked Middle Eastern to me, and I supposed he was often treated like a monster also.

Then I made a choice. I found my voice, and asked what scared him. We talked briefly. Apparently he thought that my mask was some sort of freakish costume. I explained about having multiple chemical sensitivities. I kept pulling myself back from the hurt and sadness I was feeling. I decided it was more important to connect with this man through our common humanity than to dip into the pain at that moment. He learned something about chemical sensitivities, and I learned that his name was Ali, he was lonely, and he often stands near the market to socialize with people.

When I drove away in my car, I took off my mask. I stopped briefly at the light and waved to him. He yelled out: "Hey Diana, why you wear the mask? You much prettier without it!"

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In July 2005 I stopped my work at Buddhist Peace Fellowship. BPF had been at the centre of my life for many years. I had founded the Prison Program and was still its director, and had also taken on being BPF's Associate Director. So gradually that it was hard to notice the decline, I was getting sicker and sicker. The debilitating physical symptoms (an average of 4-5 migraines per week, severe rashes, crushing fatigue, and being ultra chemically sensitive to fragrances and other chemicals) got worse to the point where I could no longer continue my normal activities. At the end I was lying down on the floor working in the dark, still thinking it was "just temporary." The symptoms had been building for years – traceable perhaps to a combination of a tick bite, the Epstein Barr virus diagnosed three decades earlier, my work at a national chemical lab (ironically as an injury prevention consultant), toxic exposures while working as a refrigeration mechanic, and/or some genetic weakness—but over the past years the symptoms had significantly worsened. It was not until a talk with Pema Chodron and Judith Simmer-Brown that I woke up to the situation's seriousness. When they and a prominent endocrinologist all told me fiercely to stop working for a year, I finally realized how sick I was.

I received a diagnosis of chronic Lyme disease, CFIDS (chronic fatigue and immune dysfunction syndrome), MCS (multiple chemical sensitivities), and heavy metal toxicity. I went on extended medical leave from Buddhist Peace Fellowship, the faculty of the Sati Buddhist Chaplaincy Program, and all my other teaching commitments. Clearly, healing these illnesses would require concentrated time and focus. I decided to frame this time as a self retreat. Two years later I'm still in it. It has been the hardest, messiest, and most rewarding retreat I've ever done. No bells; no opportunity to leave and go home; I *am* home! No possibility of leaving a note for the meditation teacher. And living with tremendous not-knowing on every level.

During this time I have dealt with the deaths of my beloved ex-partner and my second brother, as well as several friends. My mother has been hospitalized twice. I wish I could do more to help my elderly parents in Montreal than the current situation allows. At this point state disability has stopped, and I am living solely on the generosity of family and friends. I am not wealthy nor am I a trust fund baby. I am a Canadian living in the U.S., a country with brutal policies towards poor people and no universal medical insurance. And yet I am as happy as I've ever been! Go figure.

The dharma has been central to my life for many years, but I've never appreciated it more than I do now. Spending this much time alone, with so much uncertainty, physical pain, no prognosis, and the bottom of my world falling out, has been a perfect set-up for practice. Fortunately I had already been practicing for decades. I could never have imagined how challenging this retreat would be. And yet its teachings about mindfulness, patience, equanimity, lovingkindness, compassion, sympathetic joy, mudita, renunciation, and sangha have been priceless. I never would have chosen this retreat but since it chose me, I have come to appreciate its strictness. Having all identities ripped away was a tremendous shock at first. Who am I really? I keep relearning that there is no solid Diana after all!

Patience deepens each time I long to carry out one of the ten thousand exciting projects still dancing in my mind, and know that I have the energy to do just five minutes of work. Missing out on so many activities I enjoy has offered me a chance to cultivate mudita – taking joy in other people's happiness. My close friends used to protect me from stories about their pleasurable pursuits, thinking I'd be jealous hearing about them. I was sometimes, but now I get a contact high hearing their delight. Another way of tasting interconnectedness.

I feel gratitude for the many people in my communities who have stepped forward to help me. And in turn I can offer them a haven of rest from their overly busy lives. Many friends have napped in my rocking chair while visiting. Some ask for assistance with their overwhelm. I'm happy to help when I can.

There are also the people who have not felt up to relating to me now that I'm so sick. At a grief group I attended after my first brother died, one woman said that losing her husband had rewritten her address book. I know what she means. Some people literally stopped calling once I got sick. The reality of life with a chronic illness can be messy. And I'm thrilled with the new people who are in my life since I became ill. The rewriting goes both ways.

After the diagnoses, my natural inclination (as a long time social justice organizer) was to look for ally networks for people with hidden chronic illnesses. I've been doing ally work for several decades (see [TW Spring '07](#)). I was shocked to realize that such networks don't exist for illnesses like mine. Ally work for people with chronic illness is where the ally movement for people of colour was over thirty years ago. People with Lyme, CFIDS, and disabilities are all doing terrific advocacy work but I could not find groups of well people (aka "TABs" – Temporarily Able-Bodied people) doing ally work for us. People with the illnesses I have are largely unseen, and often too damn tired and sick to organize. One of the "heavenly messengers" who woke the Buddha up to the necessity of leaving the palace to seek enlightenment was a very sick man. We all know the truth of impermanence of health (among other things). Where are *our* allies?

I sometimes get disheartened at the ignorance about the illnesses I live with. Being so sick is hard enough. Enduring the losses is hard enough. We are also invisible.

And our invisibility is heightened by the fact that we look well much of the time. Plus, symptoms are often cyclical, so we are sick in unpredictable patterns. In addition to holistic medical care, it takes months of Xtreme mindfulness (my main practice now) to discern patterns and create new life practices to support healing. I used to be a "get up and go" activist. Now I nap frequently. I used to be a joyful jock. Now I exercise in one-minute increments.

Finally, the fact that many people (including some within our dharma communities) think we are not *really* sick is demoralizing. I have been told to do more therapy, and to address my neuroses. The term “yuppie flu” is still used in reference to CFIDS, even though CFIDS is more prevalent among working class Latino/as than whites (according to a 1999 DePaul University study). Public awareness about chronic illnesses is growing, but we still hear disparaging comments that even friends with us may not notice or know how to respond to. I have often been asked to coach friends after one of these incidents. “What should I have said?” they will ask me. This is exhausting and painful. I know how common this experience is from my participation in on-line groups.

The statistics on suicide by people with hidden chronic illness are shockingly high. In mid March Bill Chinnock, Emmy-award-winning composer and founding member of Bruce Springsteen's E Street Band, killed himself, apparently due to hopelessness about his chronic Lyme disease. Particularly tragic, since he'd been a long time Lyme advocate and supporter of others who live with the illness. (See www.sunjournal.com/story/203796-3/MaineNews/Lost_to_Lyme/.)

I am fortunate to have a large well-intentioned community, who are slowly learning about chronic illnesses through me. However, as we know from our work around unlearning racism, it is exhausting for folks in any target group to also be the educators. To potential allies I would say that having good intentions and a good heart is a good start, but it's not enough. The next step is to inform yourself about the challenges that people in a particular group are facing, and then walk ahead of them, taking actions to make their way easier, like the lead goose in flight formation.

Two examples come to mind: When I first visited my acupuncturist, he burned moxa (an herb used for healing) and used scented bathroom products. His healing is very skilful, but his office was making me sick. I told a friend who is also his patient, and she offered to talk to him for me. After their discussion, he decided not to use moxa on days I have appointments, and to replace all bathroom products with unscented ones. Another time, a friend who knows I'm ill bought and distributed booklets about environmental illness to several non-profits. She emailed the non-profit directors, and cc-d me, saying she wanted to support their workplace awareness about environmental illness for the sake of people currently with EI and everyone else, as we're all potential candidates.

Recently I talked with a friend who had chosen not to invite me to teach a short workshop even though my skills were a perfect match. I was upset. My friend had been focusing on my illness, which obscured my gifts and experience to her. When she remembers my wholeness, I become three-dimensional to her again. In any diversity ally work it's important to see the whole person, and not just their label. Asking for *my* assessment about whether I could do the work rather than eliminating me as a possibility would have changed the experience for both of us.

After my diagnosis I enrolled in an on-line self-help course for people with chronic illness. The course's founder then invited me to moderate a global on-line support group. I have learned a lot by reading others' stories over the last year, as well as doing my own research. I go to a holistic clinic run by an MD-acupuncturist dharma practitioner. Most of the patients have cancer. Each week we drip (receive IV's), talk together, and sometimes laugh about our illnesses. One woman walked around our circle wearing two new prosthetic breasts, and asked us each to squeeze them to assess how realistic they felt. Women bald from chemo compare wig styles and colours. Lucia decided to go fire engine red one week, then cobalt blue the next. One elderly mainstream woman made us laugh so hard we almost yanked our needles out of our veins when she described her introduction to pot culture through her medical marijuana dealer (for chemo-induced nausea).

Another day the link between environmental toxins and illness manifested right in the IV room. A man smelled unmistakably of paint as he received IV's for cancer, presumably detoxing from decades of exposure to plastics, solvents and paints. He had always lived an impeccably health-conscious life otherwise. He reminded us that we can live an individually healthy life and yet we are truly interdependent.

Each of us is evidence that environmental illnesses are increasing. Our illnesses are linked to high profits and low regard for consequences to life in the petrochemical and perfume industries www.perfumefoundation.org/. I'd like to see a film like "*An Inconvenient Truth*" made about the toxic effects of environmental devastation on our health. We are the canaries in the mines, warning of this precious planet's poisoning.

I talked with my friends Eddy and Rory recently. Between them they've done 32 years inside. We spoke about the similarities between doing time in prison and doing time with chronic illness – the lack of choices, the lack of understanding, the need for allies, AND the possibility of freedom no matter where we are.

My request for allies for people with chronic illness is actually a plea for us to be allies for everyone without exception, as our interdependence is undeniable. Our planet's fragility reminds of us this truth each moment.

Some Ways To Be an Ally

1. **Listen deeply** to the person who is ill. Put aside your own stories about illness. Listening deeply changes the listener, the speaker, and the situation.
2. Make sure you **understand** the facts and the nuanced emotional content by checking with the speaker.
3. **Inform yourself** about chronic Lyme disease, CFIDS, MCS, and other hidden illnesses that get little publicity and funding but are affecting so many. Did you know that 15 percent of the U.S. population suffers from multiple chemical sensitivities and the number is increasing annually?
4. **Speak out** when someone makes an ignorant remark about people with hidden chronic illness.
5. **Make your work place and dharma centre accessible** for people with chemical sensitivities by making them fragrance-free zones. Publicize this on all flyers, the way East Bay Meditation Center does. Berkeley Zen Centre has come up with a creative substitute for incense offerings. During service, priests sprinkle flower petals into a bowl of water at the altar. Many corporations (e.g., Kaiser) are scent-free zones since their own employees are becoming increasingly chemically sensitive.
6. **Wear fragrance-free products** yourself. See www.bpf.org/html/whats_now/FFproducts.html

What *Not* to Say...

1. *"Oh, you're tired? Yeah, I'm low energy, too."*
People with CFIDS and chronic Lyme are not merely tired; the bone-crushing fatigue is beyond description. Comparing our level of fatigue to ordinary tiredness is akin to comparing a bruised toe to a bulldozed foot. This comment is so common that it is included on a common CFIDS sweatshirt as a fundraiser for research.
2. *"You look good; are you really sick?"*
People with CFIDS and other chronic illnesses often look healthy. That's the good and the bad news. Good because who doesn't want to "look good"? However, this increases the invisibility of the illnesses, and makes it harder for people to believe that those of us with chronic illnesses are seriously sick.
3. *"Oh, you have 'chronic fatigue'? Just do X, Y, or Z. My friend did, and s/he got better in a few weeks (months, years)."*
People with any chronic serious illness are usually inundated by well-meaning friends with unsolicited ways to get well. It takes enormous energy to sort through the mountains of information. Since the medical profession is largely ineffective at treating CFIDS and other chronic illnesses we must discern our own path out of the many (often weird) possibilities offered. Ask first to see if it's wanted before offering advice.
4. *"How are you?"*
"How are you" is usually an innocent reflexive question which holds little or no meaning. For someone living with chronic illness it can be an unwelcome reminder of the illness. Consider asking: "Do you want to be asked how you are?" It shows you remember, and also have awareness about how loaded the question can be.

5. “Have you worked on X in your psychological/spiritual life?”
This can imply that I would not be sick if I had resolved my issues. Do I have unhealed places? Yes. Do I have psychological/spiritual places I’m working with? Yes. Is that why I’m sick? Way too simplistic. This is a form of blaming the victim, and a misunderstanding of interconnectedness. In any illness the physical, spiritual, and psychological levels interact in complex ways. In my own journey I’m working to address them all. Unfortunately this oversimplification has led to much suffering among people with chronic illness.

A Few Resources

Chemical Injury Information Network (CIIN)

Support/advocacy organization dealing with Chemical Injury.

www.ciin.org

Debra Lynn Dadd

Resources to help consumers make environmentally wise, non-toxic choices about products we use daily.

www.dld123.com

Princess Tiger Lily: Resources for MCS, CFIDS, fibromyalgia groups worldwide; making your workplace fragrance-free; links between MCS and Gulf War syndrome; etc.

www.princesstigerlily.com/mcs/mcs_by_area.html

CFIDS Association: Primary U.S. CFIDS advocacy group.

www.cfids.org/about-cfids/default.asp

Angelfire: Excellent worldwide resources for people with CFIDS and our allies.

www.angelfire.com/ri/strickenbk/links.html

Lyme Disease Foundation: National nonprofit for Lyme Disease.

www.lyme.org/

There is no separation. When we act in a way that protects the life of others, we are protecting ourselves, our environment and future generations.

Sentient Beings are numberless, I vow to awaken with them.

Diana Lion is the founding Director of BPF’s Prison Program, and also was BPF’s Associate Director of Programs until going on medical leave in August 2005 due to serious chronic illness. She especially wants to thank Mushim Ikeda-Nash and Larry Yang for their help with this article. She is currently living on dana – the generosity of family and friends. If you want to contribute to her financial well being, you can either email David@VillageEconomics.biz to get instructions for giving on line; or send checks made out to Diana Lion to Alan Senauke, c/o BPF Prison Program, PO Box 3470, Berkeley, CA 94703.