

## Listening to Illness<sup>1</sup>

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Allen Avenue Unitarian Universalist Church

Reading: *Grappling With Destiny* by Merrily Bronson<sup>2</sup>

To give you a little perspective on me, before I had cancer, I was what I call a human doing. ...I thrived on being busy all the time... Anyway, before I got really sick, my friends assigned me the job to just breathe. They said, “That is all you need to do. You don’t need to be doing things all the time. In your recovery, the mantra you need to repeat is, Just Breathe.”

Well, that winter I got really sick. I was on IV nutrition because I couldn’t eat. ...I got very, very weak. I called myself “the houseplant.” People would feed me and move me into places in the sun, and generally take care of me. “Just breathe” was about what I could do, and even that was hard because my lungs were filling with water. I remember one day sitting out on the deck, watching the leaves and the trees and thinking, *Do I want to fight my way back?*

...as I hung out in that deep quiet place, just breathing, ...I felt two things. One thing was that God, Great Spirit, Life, whatever you want to call it, did not care if I had skin on or not. The reality of my life on that level would go on if I was in this body or not. I wondered then, Who chooses? Do I get to choose if I live or is that the will of something greater than I am? I never got an answer to that one...

But I really got to a place where, aside from a tug of sadness about leaving my loved ones, I could see that both choices were viable. I could either live, or I could go on living without my body. Either way was okay. So I was sitting out on the deck this day and feeling the pain of human life, feeling the pain of the world, and feeling totally overwhelmed by it. I have always felt that the world needs fixing and I need to fix it, so I was really overwhelmed. At that moment, I thought, *I don’t think so, I don’t think that I do want to fight my way back. It is just too painful out there. I think I will just let go, and go on.*

I had this thought, I won’t call it a voice—it was a thought that popped into my mind that said, “*You don’t need to do anything. You just need to be an entry point for love – that’s all.*” And I realized sitting on my deck chair wrapped in blankets, breathing, that I could do that there. I didn’t have to do anything more than just open to love and let it pour through me. It would benefit the people around me and who knows, it might ripple out, across the world. There are spiritual traditions that say a butterfly’s wings on this continent will affect the weather in China. Certainly if I aligned myself with love, it would make a difference.

With that realization I thought, *Okay, I could come back.* I began to get better.

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<sup>2</sup> This reading was originally posted on a website in 2006 that is no longer available.

[http://www.lifechallenges.org/people/MrlyBrnsn\\_Grpl.html](http://www.lifechallenges.org/people/MrlyBrnsn_Grpl.html)

## *Sermon*

Illness is a natural part of human life. In our society, the most common approach to illness is that of a problem to be solved. We deal with our bodies like we deal with our cars. We expect them to be well-functioning machines that need occasional trips to the mechanic for tune-ups and repair, and replacement of worn out parts. Or we may think of the problem as a battleground: a war between our immune system and the assault of microscopic invaders such as bacteria and viruses, or the insidious expansionism of cancer cells. We look to our doctors for an arsenal of weapons to defeat the enemy.

Some have adopted a more holistic view of illness, but we carry our problem-solving approach into this realm as well. We attempt to create health by making the right lifestyle choices: the food we eat, the exercise we do, the stress we manage, the attitude we carry. Problem solving is a wonderful American virtue. With this approach we have cured many killer diseases and increased our lifespan. But problem solving is not enough.

A philosopher has said, "Life is not a problem to be solved, but a mystery to be lived." After we have fixed all that we can fix, illness still remains as a natural part of our human lives. In fact, because we have found treatments for many diseases which used to be fatal, more people face illness as an everyday part of their experience. I would paraphrase the philosopher and say, "Illness is not only a problem to be solved, but also a mystery to be lived."

We don't have to stop trying to solve its problems, or doing the best we can to live healthy lives. But sometimes we have to acknowledge that illness is bigger than we are. When that happens, we can start paying attention to illness in a new way; we can listen to illness, to see what it might teach us about being human. We can listen to illness to see what it might teach us about life.

Dr. Rachel Naomi Remen differentiates between disease and illness. Doctors diagnose diseases, but illness is the patients' actual experience of their disease. In fact, if there is some remedy for a disease that allows us to keep functioning, most of us would probably report that we are not really ill. And we don't need to have a deadly disease to feel ill. Even a common cold can wipe out our ability to accomplish everyday tasks. The flu can send us to our beds. Illness is an experience that interrupts our plans and gets in our way.

When I was younger, my experience of illness was primarily these temporary interruptions like colds or the flu. I had also put up with allergies, and an occasional bout of bronchitis. I noticed that if I was pushing through my days with an overload of stress, or burning the candle at both ends, I was more likely to succumb to one of these illnesses. It felt like a relief to be forced to my bed, and the rest felt healing to my weary soul. On the other side, if I noticed a virus coming on, I could often keep it at bay with herbs and vitamins, lots of water, and a positive attitude.

From these experiences, I became aware of the connections between my spiritual and emotional outlook, and the health or illness of my body. Illness taught me the need for quiet; I needed to have time to reflect and restore my spirit from the relentless activity of modern life. If I didn't build those rhythms into my life, illness could force me to slow down.

These were valuable lessons, but then I learned that these were not universal to all kinds of illness. When I met my partner Margy she had already lived with chronic illness for over 13 years. It didn't matter that she had been an athlete or that she ate well or exercised or rested. Illness took away her ability to earn a living or follow a career. Eventually, her doctors found medications that helped to ease some of the worst symptoms, but illness remained a constant companion on her journey.

We like to feel that we are in control of our destiny. That we can make plans and achieve goals. But serious illness shatters this illusion of control in our lives. Because we are so attached to control, those who are well often fear those who are ill, or attach meanings to illness that are blaming and hurtful to those who are ill.

Kat Duff, in her book *The Alchemy of Illness*, writes,

I have come to realize that many people are deeply disturbed by my continuing illness; they want to help but also need to reassure themselves that disasters like disease can be avoided and, if necessary, easily remedied. It's hard to swallow the fact that we have little or no say over the extent and timing of our illnesses. ...Sickness, by these definitions, is not only a breakdown of normal health, but a personal failure... When symptoms persist and illness becomes chronic, we often find fault with the victim, we call it a lack of will power, a desire for attention, an unwillingness to work or change, rather than question the hidden assumption that it is within our power as human beings to overcome sickness...

Another person with a chronic illness, Cheri Register, writes,

One of the first questions that the newly unhealthy ask is "Why me?," which poses yet another dilemma: Either you are special and have been given a unique opportunity to transcend ordinary human experience, or you are deficient and have been given a penance to pay to atone for your deficiency. Feeling exalted and feeling unworthy are really two sides of the same coin: a conviction that you must be different from everyone else or this wouldn't be happening to you. ...It's easy to overlook the fundamental truth that who gets sick is a random, arbitrary matter with no [individual] moral implications."<sup>3</sup>

Through Margy's experience, and that of other friends facing serious illness, I came to understand that illness and health were much more mysterious than could be explained by a mind-body connection. Then several years ago, I myself developed a chronic illness—auto-immune thyroid disease. For some people it can be managed entirely by medication, but for me, it became more complex. It has led me into a whole new relationship with illness, and I have had to learn new ways of listening to the needs and demands of my body. Eventually, it compromised my energy enough, that I made the decision to retire from full-time work this year.

Cheri Register subtitles her book about chronic illness, "Embracing the Imperfect Life." She writes, "How well people manage lives marked by illness depends not on the nature of the illness but on the strength of their conviction that life is worth living no matter what complications are imposed on it."<sup>4</sup> She goes on, "Life is imperfect. This is the most important lesson that chronic illness teaches. Life offers us both joy and suffering, and not always in balance. To have one, we must make our peace

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<sup>3</sup> Cheri Register, *The Chronic Illness Experience: Embracing the Imperfect Life*, (Hazeldon edition, 1999), p. 36.

<sup>4</sup> *Ibid.*, p. xxii.

with the other. That is the reality we live, the reality we cannot gloss over or pretend away when we are sick.”<sup>5</sup>

Dealing with chronic illness in our own life, or with someone in our family is an exercise in opening the heart to life as it is. On one day Margy and I might be able to go out to work in the garden. On another day, she might have to stay in bed without enough energy to even read a book, or I might have to take a nap in the middle of the day. To live such a life with serenity requires both of us to practice flexibility and spontaneity; we can't be too attached to our plans. Instead, we must find our joy in whatever gift the day offers.

Dr. Remen tells a story from one of her patients: “Before I got sick, I was very certain of everything. I knew what I wanted and when I wanted it. ...I walked around with my hand outstretched saying, ‘I want an apple.’ Many times life would give me a pomegranate instead. I was always so disappointed that I never looked at it to see what it was.”<sup>6</sup> When we open our hearts to life as it is, we discover the tastiness of the pomegranate.

Illness teaches us that human life is not just about doing things, numbering our accomplishments or working hard. It is not about achieving goals and winning. As Unitarian Universalists, we affirm the sacredness of life. Illness challenges us to make good on that affirmation. Those who are ill might be unable to do the things that win the approval of society or the accolades of their neighbors. Some might be unable to make their own meals, or take care of their washing and dressing. But from illness we learn that human life is first of all about *being*. We learn that being itself is sacred.

Kat Duff describes coming to this awareness in the midst of her chronic illness:

I remember the exact time and place I first realized its enormity; I was sitting on the living-room couch after a long, tiring morning of work, holding a small bowl of rice in my hands. The phone rang, and--quite out of character--I just sat there and let it ring, as I turned the bowl in my hands and admired its perfect shape.

I felt privy to one of the world's great secrets: that what *is* is enough, that each moment contains, like the circle of that bowl, the whole of creation in the space it offers, and we need not go anywhere or do anything to find it. Since then there have been times when I have cried bitterly over the losses wrought by my illness, but more often than not I have cherished the serenity of being still and feeling full with the moment at hand, of not wanting anything more than I already have.

To achieve a sense of serenity about one's illness is complicated in our society by the high priority we place on independence. It is complicated by the very real problem of how to survive financially when illness takes away the ability to work. Our systems of support for those who are ill are woefully punitive and inadequate. Our society values those who can make money, and casts aside those who cannot.

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<sup>5</sup> Ibid., p. 317.

<sup>6</sup> Rachel Naomi Remen, M.D., *Kitchen Table Wisdom: Stories That Heal*, (Riverhead Books, 1996), p. 176.

Listening to illness teaches us that human beings need each other. We are not meant to be totally autonomous, always functioning, providers of all our own needs. An old friend of mine lived with cancer for many years before she died. She had always been an independent person, successful in her career as an executive in the business of elder care. She was compassionate and strong, like many women in care-giving work. When she was being treated for cancer, all of the ancient foundations came tumbling down; she was face to face with her own vulnerability.

A few of her friends weren't able to deal with the floodgates of raw emotions that poured out of her. But others were the lifeline that held her and nurtured her, and sustained her through the ordeal of chemotherapy and radiation. Cancer, and the love of her friends, taught her that she didn't have to keep performing. She could be her authentic self, with all of her strengths and her needs. Ultimately, she described it as a great gift.

A similar story is told by a woman named Mary Jackson after her cancer diagnosis.<sup>7</sup> She wrote, "As an Afro-American woman, it is not in our culture to talk about things, ...we never discuss the 'C' Word. ...I was really blessed to have such a very caring doctor. She asked me to humor her by getting a biopsy... One week later she called me... She said, 'We need to talk, and I don't want you coming out here by yourself.'" I went into shock.

My oldest son is about six feet tall and he saw the expression on my face. I was on my way downstairs, because I have a tendency to go to my kitchen and cook when I get upset. Well, he was constantly on my heel asking me what was wrong. I kept saying "Nothing". But when I got in the kitchen, I turned around, and there he was, this big tall guy, and I just fell into him and started crying.

For the first time in my life, I had to stop and tell my family that something was wrong with me, and I wasn't used to doing that. Before that, I took care of everything. I was the rock of my family. ...But this time, I couldn't do this. This was too big. I couldn't do it by myself. ...I realized that for the first time I didn't have to do everything. My friends and family surrounded me. I never realized that I was loved until I got cancer. I never realized that people appreciated me until I got cancer. ... my church family also just overwhelmed me with so much love.

In the Christian scriptures, Jesus speaks of six actions that will matter in the final judgment. They are all about taking care of each other. In one, he says, "I was sick and you visited me..." Illness brings us face to face with our need for each other. Whether that need is emotional, or financial, or literally physical, it is a basic part of our human condition. Illness shatters the illusion of independence. It *is* an illusion that we can get through life on our own devices. We start out as totally dependent infants, and we often end up needing similar care at the very end. Illness challenges us to face the dependence which is part of being human.

To face dependence brings up all the issues of our early childhood, when we were dependent on our parents. Was dependence a feeling of warmth and nurture and safety? Or was it a feeling of fear or deprivation or danger? Our need for independence and control may be rooted in childhoods where dependence was linked to pain or humiliation. Perhaps we had to carry large responsibilities at an early age, because our own parents were out of control or overly dependent upon us when we were too

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<sup>7</sup> Originally posted in 2006 on a website no longer available: <http://www.lifechallenges.org/people/jackson.html>

young. Even if our childhoods were content, our whole culture teaches us to associate dependence with a loss of dignity.

But dependence can also open the door to some of the best parts of being human. I have sweet memories of little illnesses in my childhood. A bed was made up like a nest in the living room, with cool sheets and fluffy pillows covering the scratchy fabric of the couch. When my sisters went off to school, I was tucked in there, watching TV or playing with games or sleeping. I can still taste the brown sugar toast and applesauce, weak tea and watered-down orange juice my mother would bring for my breakfast. Her tender loving care was like a warm homemade quilt, like a kiss to make everything all better.

In the heart of each one of us lives a child who wants to be loved and nurtured just for being who we are. Left to our own devices, we also create and work and build lives for ourselves. But at the core, love is not about what we can accomplish or give, but an unconditional embrace just for being.

This love is a balm that can soothe our souls. This love is the root of all healing. This love enables us to bear the mystery of illness in our human lives. As Merrily Bronson learned sitting in her deck chair wrapped in blankets, just breathing, we don't need to fix the whole world. It is enough to be an entry point for love.

#### SILENT MEDITATION

HYMN                      Meditation on Breathing                      #1009

#### BLESSING

Human beings need each other, and we are a blessing to each other.

Each of us can be an entry point for love.

I invite you to participate with me today in a shared silent blessing.

I invite you to stand as you are able, and turn to a person near you, if someone needs to remain seated, another who is standing should come to them, or if anyone is alone, draw them into a circle of three.

Each of you place your right hand on the other person's shoulder; or if it feels more comfortable, you can take both of each other's hands in your own.

I invite you now to silently bless each other.

Imagine that love is flowing from your hands into the body and spirit of the other.

Imagine the grace of that love, its power to heal, to comfort, to join together.

Let yourself also receive the love which is flowing to you from the other person's hands.

We are all sacred, just the way we are, just by being.

We don't need to fix the whole world. It is enough to be an entry point for love.

Hand in hand, we will touch the mystery.