



Illness as a Pilgrimage

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There is a difference between a journey and a pilgrimage. With a journey, there is a particular destination in mind. With a pilgrimage it is the process that matters. Each step is sacred. You take the first step, then the next, then the next. In this column I want to share with you a personal pilgrimage that I did not choose, but one that has offered many gifts and discoveries.

A year ago I came down with my annual bout of winter bronchitis. As an asthmatic, I'm particularly susceptible to bronchial infections. This was a bad one, and my husband, Ellis Ralph, and I had it for 3 months. We cancelled everything, including church. I was up all night coughing, and that kept my husband up, and neither of us got much sleep.

We are members of St. Paul's Episcopal church, and we were on the prayer list. Since we couldn't go to church, the Rev. Suzanne Stoner brought communion and church to us, which really touched us and helped us feel more connected.

Ellis recovered, and I started to feel better during the day, but I would still have this terrible cough at night. During that time, I felt like I was going downhill, and I didn't know why. I had very little energy, and started losing my enthusiasm for things that used to matter to me, like music and working with people who are integrating their spirituality and their work.

A year ago I was hired to do two "Leading With Soul" workshops in Canada for faith-based organizations. I had been very excited about doing these workshops, but I now had a hard time concentrating as I put the materials together. And I felt a sense of dread about the actual workshops. I didn't know if I would get enough sleep the night before and be able to be attentive and present during the workshop. Or if I might end up having coughing fits and not be able to talk. That had happened to me in the classroom a couple of times in the past, and it was horrible.

I went back to the doctor several times for antibiotics and steroids, but they didn't help. After six months, my doctor recommended I see a pulmonologist, and it took three more months to get an appointment.

The appointment with the pulmonologist in September began with an hour of breathing tests and a chest x-ray. The tests were followed by a short meeting with the pulmonologist. He said, "Do you know what COPD is?" I answered, "No, I've heard of it, but I don't know anything about it."

He explained that I have Chronic Obstructive Pulmonary Disorder, with permanent lung damage. He told me that this disease is progressive and irreversible, and there is no known cure. I went into shock. The doctor told me a couple of things about daily medications I need to take. One is an inhaled steroid, and I had heard that steroids were bad for you, so I asked how long I would have to take it. "For the rest of your life," he said. He asked if I had any questions, and I was too stunned to think of anything to ask.

Being the good academic that I am, when I got home I immediately started learning everything I could about COPD. I learned that it is the third leading cause of death in the U.S. That was not comforting. It is nicknamed the "smokers disease," and the main recommendation for slowing the progression is to quit smoking. That was no help, since I don't smoke. I learned that the average time from diagnosis to death is five years, but that there are some people who have lived with the disease for 20 years or more. That was scary at first, and then comforting. I told myself, "Well at least I don't have lung cancer." And if I have at least five years left, I'll take it.

Before this diagnosis, I thought about death frequently. I'm not morbid about it, but I am deeply interested. This interest stems from a near death experience I had when I was 26. I was an atheist at the time, and the near death experience changed my belief instantly when I found myself merged with God's love and power. There is no way to describe the joy and ecstasy of that feeling, but in spite of it, I asked to come back because I had just given birth to my son. I believed that asking to come back was breaking all the cosmic rules, but I immediately found myself back in my physical body and in my hospital bed.

For years I thought that I was the only person who had died and returned, and I did not know what it meant. But I did know that I was sent back for a reason. It felt like this huge burden. I was "just a housewife" at the time, and who was I to save the world? That's what I thought I was sent back to do.

In my thirties, I came across the research of Dr. Raymond Moody on near death experiences, and discovered that I was not the only one who had had this experience. Almost all near-death-experiencers return with a strong sense that they are here for a reason. I later came to understand that whether or not we have had a near death experience, everyone of us is here for a reason.

As a result of being diagnosed with COPD, I was compelled to look realistically at my life and death. For some reason I can't explain, a beautiful peaceful acceptance came over me. I'm sure that most of us at sometime wonders how we might die. Will it be

in an accident? Will it be a slow and painful death like from cancer? Will I die suddenly from a heart attack or a stroke? Or will I be lucky enough to die peacefully in my sleep at some old ripe age?

With the COPD diagnosis, I had a very clear idea of how I was likely to die. I was diagnosed with Stage 2 COPD, which means some permanent lung damage and getting out of breath pretty easy. Stage 3 means having to be on oxygen and having very little energy to do the things you love. Stage 4 means frequent hospital visits for serious lung infections and finally death. It felt weird to be able to say, “Okay, now I know how I’m going to die. The medical system has lots of experience with these stages and they will make me as comfortable as they can. With God’s help, I think I can handle this.”

Rabbi Zalman Schachter was a guest speaker via webcam at St. Paul’s about three years ago. We were able to ask him questions, and at the time he was quite elderly. I asked him how he felt about his own death and the process of dying. He told us that every single human being knows how to die, and that, in fact, no one has ever failed at it. At that time, I found his insight quite comforting, and after this diagnosis, I thought about what he had said a lot. I began to read his book “From Age-ing to Sage-ing” where he focuses on our later stages of life and offers thoughts for conscious living and dying.

At 68 years of age, I have outlived most of the members of my family, and to me each day is a gift. Carlos Castaneda talks about death as our ally, and describes death as always being beside us. Eastern traditions teach us that contrasts make our lives more whole and integrated. An awareness of our mortality has the potential to make us feel more alive and in the present moment. While no one can know for certain about what happens when we die, my near death experience gave me a taste, and it is indescribably beautiful.

I found myself getting very focused about what matters most to me and what I want to do with the time I have left. My husband and I had some difficult and honest discussions about what my terminal diagnosis meant for us. While I knew it would likely be several years, it was heart-wrenching for me to realize that he would have to take on more and more responsibility as my disease progressed. We are partners in every way, and I have always been able to do my share. Ellis was so lovingly supportive and willing to make whatever changes we needed to make to support my health. I felt so blessed.

I thought about my business, Edgewalkers International. This is a consulting company I set up nine years ago to support businesses and leaders in their integration of faith, spirituality and work. I have a network of people trained in my work, and we had been poised to really begin expanding in the next couple of years. But what if I couldn't travel anymore? And what if I didn't have the energy to do the work that has meant so much to me? I needed to start thinking about letting go of

all that, and about developing people to take on more of what I have been doing. That was hard, because this work has truly been my passion and my calling.

But the top priority was to take care of my health. I was committed to taking the medication prescribed by the doctor, but I wanted to see what else I could do. Ellis and I are very involved in the Fayetteville community, but we made a decision right after my diagnosis to cancel just about everything we were involved in. We host house concerts and Edgewalker Cafes, and we attend all kinds of events around town, keeping us busy many nights of the week. But we just stopped. We wanted to take the time to sort out what we needed to do, and how we wanted to live our lives with this illness. Most of all I wanted the time to do the things I often advise others to do; to live a more balanced life that takes care of body, mind, emotions, and spirit. For me this means taking time to meditate, read, exercise, and to write and play music. When we are so involved in community events, these self-care activities seem to fall by the wayside. Now they had to be the main focus.

I reached out to friends and family for support, and people began making suggestions about alternative approaches I might try. Every day became filled with healing activities. Each of these sessions and approaches became a step on the pilgrimage.

St. Paul's has a Healing Touch ministry that is available to anyone in our Northwest Arkansas community who needs it and I took advantage of that. I also went to a

chiropractor, an acupuncturist, qi gong classes, and meditation classes. I gave up gluten and dairy, began using essential oils, and went to energy healers. I felt desperate. Anytime someone suggested something, I said yes. I thought to myself, “This is what someone who has just been diagnosed with cancer or other life-threatening disease must feel like.” You want to trust the doctors, but you don’t know if you do. And if faith and spirituality are very important to you, you may feel called to look into spiritual approaches to healing. However, one of the drawbacks to this kind of desperation is that you might exhaust yourself financially and physically, looking for alternative solutions.

But I so wanted to prove the doctors wrong. I wanted to prove that an irreversible condition can be reversed. I wanted to prove that alternative and spiritual healing approaches may work as well or better than allopathic medicine. And I think my ego wanted me to be the special case that beats the odds.

The people who worked with me frequently said, “I don’t think you have COPD, I’m just not sensing it.” And I would reply, “Well, I flunked the breathing tests, and when you get a number below the threshold, you are diagnosed with COPD.” One minister friend said, “I am praying for your full health and well-being, and I have a vision that the next time you go to the doctor he says, ‘I must have misdiagnosed you.’”

Something about that vision felt right to me, and so I envisioned that in my meditations.

People would send me links to interesting medical research in journals, and I learned that singing and walking have both been found to slow or halt the progression of COPD. I love to sing, and I love to walk, but usually I think I'm too busy to do these things. Now I had a good reason, and so I began doing both on a regular basis. It was wonderful that the things that nourish my spirit would also nourish my body. My health began to improve dramatically. I began to feel better than I have in years, and have been full of energy, optimism, and inner peace.

In November I returned to the pulmonologist. This time I brought Ellis with me because I knew that a second pair of ears can be helpful in stressful health situations. I had a long list of questions about alternative COPD treatments that I wanted to try. The doctor was not interested in any of these because they are, according to him, not based on mainstream science that has been reviewed in the top peer-reviewed journals. After several questions he said a little impatiently, "Look, you don't have COPD. You have chronic asthma. It is not progressive and maybe even slightly reversible." Once again I was stunned. Essentially I heard him say, "I misdiagnosed you." Or perhaps he was saying, "You didn't really understand me when I told you your diagnosis in September."

Ellis and I left his office that day with a huge weight lifted off our shoulders. On this pilgrimage I now take the next steps to health and life. The rational part of me explains this turnaround as miscommunication on his part. But I know he explicitly said in the first visit, "You have COPD, and it is progressive and irreversible." The

spiritual part of me explains this in terms of the power of prayer, love, intention and community support. But really, it is all a mystery.

I was very aggressive in finding ways to deal with my prognosis, and I got lucky. I received the gift of having to face my mortality once again in my life, and I also have the gift of not being ill.

Not everyone is so lucky. I have friend with a serious terminal illness whose faith is stronger than mine, and who has incredible loving support. There is no likelihood she will have a “mis-diagnosis” or an improvement in her health. Yet she is an inspiration to many. She is focused on being loving, giving, and authentic. She created a group called “Heaven Bound” for those diagnosed with terminal illness. What a beautiful thing to do! I believe we are all heaven bound, but a serious illness really brings that to the foreground. And I would never want to communicate that someone who gets healed is more spiritual than another. It’s just not true.

I hope that I can hold on to the sense of sacred pilgrimage that I gained from this experience. I want to remember how precious life seems when we know it may be short. I want to remember how loved I felt by family and friends. I want to remember that sense of peace and acceptance that I knew came from the Grace of God. My prayer is that each of us can see and feel the sacredness of every step on this life pilgrimage, whether we are feeling healthy and whole, or whether we know we are heaven bound due to a terminal illness.

I close with a quote from Louise Erdrich: "Life will break you. Nobody can protect you from that, and living alone won't either, for solitude will also break you with its yearning. You have to love. You have to feel. It is the reason you are here on earth. You are here to risk your heart. You are here to be swallowed up. And when it happens that you are broken, or betrayed, or left, or hurt, or death brushes near, let yourself sit by an apple tree and listen to the apples falling all around you in heaps, wasting their sweetness. Tell yourself you tasted as many as you could. "

Bio:

Dr. Judi Neal is the former director (retired) of the Tyson Center for Faith and Spirituality in the Workplace at the Sam M. Walton College of Business, University of Arkansas, and is currently Chairman and CEO of Edgewalkers International. Judi is recognized as an expert on spirituality in the workplace and speaks and consults internationally. She received her Ph.D. from Yale in Organizational Behavior. In 1988 after working in the corporate world, Judi began teaching management at the University of New Haven. She focused her research on business leaders who have a strong commitment to their faith and spirituality, and began studying how they

bridged the spiritual world and the material world of business. That led to her research on people she calls “Edgewalkers.”

Judi authored the book *Edgewalkers: People and Organizations that Take Risks, Build Bridges and Break New Ground*; co-authored *The Spirit of Project Management* with Alan Harpham; and is editor of the *Handbook of Faith and Spirituality in the Workplace*. She recently published her fourth book titled *Creating Enlightened Organizations: Four Gateways to Spirit at Work*. She has published widely in academic journals and has created an international community of Edgewalkers. One of her deepest spiritual practices is songwriting and singing, and she has produced a CD titled *The Journey*.