



NEIGHBORHOOD UNITARIAN UNIVERSALIST CHURCH

Faith and the Narrative of Illness

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Rachel Naomi Remen tells us this story about the paradoxical way in which the symptom of pain, can direct us in the discovery of wholeness and healing. She writes, "A woman with heart disease and chronic angina once told me of the downside of the surgery which had relieved her symptoms. Before this surgery, she had suffered frequent chest pain from her disease. Over the years she had modified her diet, learned to meditate, and had been successful in controlling most of her pain. Yet some of her pain had been resistant to her efforts. Paying very close attention to this, she had been shocked to notice that she experienced pain when she was about to do or say something that lacked integrity, that wasn't really true to her values. These were usually small things like not telling her husband something that he did not seem to want to hear, or stretching her values a bit in order to go along with others. Times when she allowed who she really was to become invisible.

Even more surprising, sometimes she would know this was happening, but sometimes the chest pain would come first, and then, examining the circumstances which provoked it, she would realize for the first time that she had been betraying her integrity and know what it was that she really believed. She had learned a great deal about who she was in this way, and though she was physically more comfortable [after the surgery], she missed her 'inner advisor.'" (76).

The stories of ill people, doctors and patients, from *Kitchen Table Wisdom* remind us that we each carry stories, in fact that our whole lives are stories. But in particular, Remen asks us to pay attention to the stories of those who are ill, believing that real wisdom can be found in those stories.

When was the last time you were ill? Your last illness, was it a small cold or a major disease requiring hospitalization? Perhaps it is ongoing, a chronic illness which has lasted a long time, and even now, is an unforgettable part of your life. When was the last time someone you loved was sick? What was it like? The particular illness does not matter as much as the story of what it means to you, and the meaning that we find in it. Like Remen, I believe that stories are how we make sense out of our lives, and illness, is one of those inescapable parts of being human which we all experience. So when I say illness, what is the story that comes to your mind? Suffering? Disease? And what is the story connected to that ever elusive and longed for word, healing? Healing.

Arthur Kleinman is a psychiatrist at Harvard Medical School and also a professor of Anthropology at Harvard University. In 1962 he wrote a book called *The Illness Narratives: Suffering, Healing and the Human Condition*, which primarily looks at people suffering from chronic pain, and takes a narrative approach to understanding their illness and their healing. Rather than the terms of disease and diagnosis, Kleinman is interested in the personal and intimate meaning that each illness has as part of a person's life story. Thus understanding narrative, or our own stories about us and our experiences, is the only way to unpack what a particular illness and also healing means to each person. Kleinman explains that there is a deep responsibility on the part of a practitioner, that is, the doctor or other staff, to listen to the narrative of a patient, not only as empathetic witnessing, but as a way *together* make sense of, and give value to the experience of being ill. This is where healing takes place and it is fundamentally a moral endeavor.

Kleinman moves from discussing the healing found in narrative to something like theology. He writes, "The moral lesson illness teaches is that there are undesired and undeserved pains that must be lived through, that beneath the façade of bland optimism regarding the natural order of things, there is a deeper apprehension of a dark, hurtful stream of negative events and troubles. Change, caprice and chaos, experienced in the body, challenge what order we are led to believe—need to believe—exists. Disability and death force us to reconsider our lives and our world. The possibility of human transformation, immanent or transcendent, sometimes begins with this disconcerting vision." (55)

In other words, the possibility of human transformation, of something holy and healing, can happen because of our confrontation with illness. Illness is a disturbing rupture in our daily lives and it disturbs our

view of ourselves as healthy, independent, and invulnerable. Illness brings us to face the reality of our bodies, our limitations and mortality. It challenges our belief in a well-ordered, controllable world. Illness is an unwelcome presence in all our lives, and yet, what a transformation of ourselves can happen because of illness. This type of transformation is independent of cure of a disease. Cures remove or reduce the symptoms of physical distress, human transformation in how we perceive ourselves, our relationships, and our purpose in the world may bring us more wholeness, more awareness, more spirit. In Leonard Cohen's song, "Ring the Bells," he sings, "There's a crack in everything, that's how the light gets in."

Like the woman in Remen's story who found that her heart pain was connected to her own personal integrity and who learned to trust this wise advisor, we too can look at our experiences of pain and loss to discover what they might be teaching us. In fact, many of us may have already found a deep and spiritual wisdom that comes from our own experiences of suffering or from witnessing the suffering of others. Others of us may be struggling with the pain and loss associated with illness, and a meaning to suffering seems difficult or impossible to find. Even though over time wisdom may be gained through illness, this does not mean that the suffering of illness is deserved or desired. Often, the meaning we find seems paradoxical in contrast to the terrible reality of illness. A woman living three years with cancer told Remen, after marveling over her inner changes and awakenings since her diagnosis, "Who would have thought I could have so much more joy in life and have cancer? Who would have thought that such a thing was possible?" (109). Through examining the stories of those who live with illness we discover strength, faith and courage. Their wisdom informs our personal faith, and sharing our experiences and our wisdom can inform our whole community.

Why must we as a community share experiences of illness and of healing? The debate over healthcare in our nation's politics is on-going, involving complex policies, insurance claims, and arguments over costs and human rights. Rarely are the stories of what illness means to individual people and families told. In addition, if you have ever been in a hospital, you know that it is a complicated and often-confusing system which includes various teams of professionals, extremely specialized language, constant questioning and testing, interrupted sleep schedules and mediocre food. How often do your doctors and other healthcare professionals take the time to sit and listen to your "illness narrative," to listen to who you are as a person, not just as a patient? And finally, our society is ever obsessed with youth, independence and self-reliance, and a certain definition of health, as looking like you belong on the cover of a magazine, and a strict avoidance of those topics we consider sad and depressing—those classic three that the Buddha set out to find answers to -- sickness, old age and death.

In contrast, as religious communities we are dedicated to supporting one another through the toughest of life experiences, to bear witness to one another's suffering and to journey together to find meaning and hope in the midst of these. Moreover, as spiritual people we see that health does not only mean being physically well, but health must also include mental and spiritual wholeness and a deep interconnection with what is holy and life-giving. In this way, as a religious community, we can be counter-cultural, upholding a different understanding of illness and health, a vision which arises from the stories of our lives, rather than the medical terms that we are labeled with.

How do we as Unitarian Universalists do as communities for sharing stories of illness and healing? As a chaplain, I frequently have patients and family members tell me, "When I get out of the hospital, I'm going to have a great testimony," or, "I look forward to telling my church about this as a testimony." Testimony, meaning giving witness or providing evidence to the way in which God or the divine was experienced in one's personal life, and told in a public way so as to prove what is true, is a common practice in some of our neighboring Christian churches. However, it is not a word frequently thrown around in UU circles. Although we have wonderful pastoral care groups and visit members who are sick, and we light candles of hope and remembrance for ourselves and others who are in need of help and healing, we are averse to talking about "faith healing," and rarely make connections between the secular medical terms of illness and our own spiritual language. So I often wonder, what would a UU testimony of faith during a time of illness look like? What would a UU theology of healing from illness sound like?

Let me read you another story from *Kitchen Table Wisdom* which gave me a glimpse of something like a UU testimony to the power of the interdependent web of life. Remen tells us about an 85 year old man who came to her to discuss whether or not to have a surgery for cancer in his lung. His eventual decision to have the surgery was influenced by a dream. "He had been sitting in his chair in the evening, reading his paper, and had almost nodded off. It seemed to him that his wife had come to sit with him. She looked much as she had in the early days of their long relationship, and as she looked at him he was struck by the love he could see in her eyes. As they sat together he could feel his fear easing a little and then he noticed that one of his oldest friends had also come into the room and was standing behind his wife's chair. His face too reflected the love that had cemented their lifelong friendship. He was smiling at this friend when he saw his brother standing beside him, his eyes filled with love too. One by one, others whose lives had touched his in a loving way were there, family and friends, teachers and students, children and grandchildren, and even family pets....No longer alone with his decision, he felt fear release him and knew then that the surgery was the right thing for him to do, no matter if he survived it or not.

Remen said, "What a beautiful thing." The man replied, "Yes, and most of those people are dead now. He smiled at her look of surprise. "I guess anything good you've ever been given is yours forever." (166). The gifts of love we receive from all the people in our lives, are ours and will accompany us in even in the midst of painful and difficult decisions.

When I read this story it reminded me of a favorite hymn of mine, "What wondrous love." As the lyrics state, "What wondrous love is this, O my soul, O my soul, that brings my heart such bliss, and takes away the pain of my soul." When I did some research on this hymn, I found that it was written in the mid 1800s as a Christian hymn, and that the love the hymn originally described was God's love shown through Jesus Christ. In true Unitarian Universalist revision fashion, the second stanza of our hymn reads, "When I was sinking down, sinking down, beneath my sorrow's ground, friends to me gathered round." The last stanza states, "To love and to all friends, I will sing, who pain and sorrow mend, with thanks unto the end, I will sing." Like the man describing his dream to Remen, we think of our interconnected web of friends, family, and community, who gather around us in love. This love heals our fears and the pains of our heart, and we understand that we do not go through our sufferings alone.

Remen writes, "The tools and strategies of healing are so innate, so much a part of a common human birthright, that we believers in technology pay very little attention to them. But they have lost none of their power. People have been healing each other since the beginning. Long before there were surgeons, psychologists, oncologists, and internists, we were there for each other. The healing of our present woundedness may lie in recognizing and reclaiming the capacity we all have to heal each other, the enormous power in the simplest of human relationships: the strength of touch, the blessing of forgiveness, the grace of someone else taking you just as you are and finding in you an unsuspected goodness.

Everyone alive has suffered. It is the wisdom gained from our wounds and from our own experiences of suffering that makes us able to heal. Becoming [a medical] expert has turned out to be less important than remembering and trusting the wholeness in myself and everyone else. Expertise cures, but wounded people can best be healed by other wounded people. Only other wounded people can understand what is needed, for the healing of suffering is compassion, not expertise." (217).

Many of our UU principles are useful in creating a framework for a UU faith in a time of illness. Our commitment to the inherent worth and dignity of each life, our integrity as persons with meaningful lives. Our covenant to one another's spiritual growth, in other words, the growth that can happen through suffering and the ability to share and encourage one another in these journeys as a community. And our understanding of the interdependent web of existence in which we all are a part, our connectedness to one another and all of life, even when sick, even when healthy. As Mary Oliver writes in her beloved poem, "Wild Geese," "Tell me about despair, yours, and I will tell you mine." "Meanwhile the world is calling to you and offering itself to your imagination, and announcing "your place in the family of things." In this

poetic UU vision, through our vulnerability and our despair, we are part of a divine and interconnected world, natural and transcendent and loving.

I have a vision of UU churches as places for healing and wholeness. For upholding stories of our illness and suffering, and bringing a holy intention of listening and witness to our stories. Remen states that people have been healing each other since the beginning of time, that we have an enormous capacity to heal one another through compassion. This is not a new truth, but it is one of which we need constant reminding. When was the last time when you were ill? And when was the last time when you were healed? May we all remember our own woundedness and our own wholeness. May we find the wisdom of our own suffering, may we find that transcendent and holy vision that can arise out of a confrontation with life's harshest pains and losses. May we as a spiritual community find healing amongst ourselves and share stories in order to heal one another. May it be so, blessed be and amen.