

Medicine and Meditation

Conversations on Mindfulness in the Management of Chronic Pain and Illness

A book of twelve interviews with prominent physicians, psychologists, Zen teachers, and those who suffer from chronic pain and illness, incorporating meditation into their medical management programs.

*Interviews by
Nancy Welch, MS, PC*

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Conversations on Mindfulness in the Management of Chronic Pain and Illness

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Dedication

For my parents who never saw illness as an obstacle.

For my sisters, Cathy and Paddy—the fights,
the love, and ultimately,
the forgiveness

and for John, always.





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Preface

Nancy Welch, MS, has brought together dedicated long-term practitioners of meditation to engage in a discussion about meditation and illness, creating this book. Her interviews were initially conducted on the Parkinson's recovery radio program of Dr. Robert Rodgers. It soon became evident that the topics expertly brought forth in her interviews extended beyond Parkinson's disease and across a much broader range of human experience. In the book, meditation is discussed from the perspective of individuals who have a chronic illness and/or disability and from the perspective of caregivers, family members and friends. Nancy's own experience includes both perspectives. As described in the book's initial chapter, she has had severe arthritis since childhood, and during the course of the interviews, both of her parents became seriously ill and died.

The constellation of interviews in this book comes from a diversity of individuals and experience. Included are Zen priests, psychotherapists, authors, artists, physicians, teachers, a computer programmer, a medical researcher, a broker, and a botanist. The interviews also come from mothers, fathers, children, family member and friends. Initial conversations focused on Parkinson's disease, but the topic quickly broadened to other types of illness including Alzheimer's disease, autoimmune disease, disabling arthritis, cancer and mental illness. The conversations discuss practical issues, for example meditating with disability, tremors, fatigue or pain. At the same time the interviews delve deeply into mental, emotional, psychological, spiritual and religious concerns that arise for the person who suffers from a chronic illness, and for caregivers and family members. Links to additional sources of information are included. The initiative, time and effort that Nancy Welch has taken to prepare this book is deeply appreciated. It is hoped that the information will be useful to readers.

J. Lee Nelson, MD

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So many people have supported me through this project I would need another book to thank them adequately. If I fail to mention you, please know there is no intentional slight; you are all in my heart and in these words.

I want to give special thanks Robert Rogers (parkinsonsrecovery.com), who suggested I write this book and showed me how to make it happen. Robert, you are a gem!

I also want to thank Robert's partner and one of my oldest and dearest friends, Deborah Russell, for sharing Robert and her home and most of all her friendship so it could happen.

To all the beloved and supportive members of Red Cedar Zen Community and the Mountain Rain Sanghas, without which I would have no practice, I want to give my very sincere thanks—especially to Tim Burnett, Florence Caplow, Connie Martin, Karen McMains, Janet Martinson, Marti Bartlett, Sandy Taylor, Joan Dow, Jack Duffy, Kate McCandless and Michael Newton for all their years of love and support, and for believing in me as a teacher and a writer.

I want to give a very special thank you to all the interviewees for sharing their wisdom and experience with such generosity and candor.

I also want to offer special thanks to Mary Lynn Lyke for her brilliance with editing all this, and the wonderful Dr. Steve Rubey for suggesting she look at my work. Thank you as well to my big sis Cathy Welch-Eckey for putting all the pieces together for me, just like when we were little.

And last but nowhere near least, for Zoketsu Norman Fischer, unflappable teacher, mentor, and beloved friend. Thank you for all you have given me through your wisdom, humor, and enlightened teachings.





Nancy Welch, MS

A Life's Journey to Joy

When I first began this project, I had no idea that I would experience such sudden suffering and the ultimate loss of my parents, one to the complications of cancer and compromised lungs, one to the fogs of Alzheimer's disease.

Writing this book, I had interviewed many people with different health issues, but never thought of my own family as being so vulnerable to suffering, incurable disease, and for my father, a protracted, agonizing death. Although the first Noble Truth of Buddhism is that life is suffering (or in a broader sense, “duhkha,” a Sanskrit term meaning dissatisfaction, the anguish of being caught in a constant cycle of craving and aversion) and although this truth tells us that sickness, old age, and death are inevitable, I had somehow managed to avoid applying this truth to those I had relied upon all my life.

Throughout most of my life, I was the “sick” one in the family. I developed Juvenile Rheumatoid Arthritis (JRA) when I was just seven years old. Three hundred thousand children in the United States have been diagnosed with JRA, a disease that destroys the lining of the joints and deforms the bones.

My parents alternately doted on me—allowing me outrageous temper tantrums whenever I felt angry or depressed and letting me stay home from school whenever I complained of pain—or else they

pushed me to not “give in” to the pain and try to do as much as was physically possible. Both these approaches left me angry and confused. The many rounds we made from doctor to doctor trying to get a definitive diagnosis (in the early '60s, in St. Louis where we lived, JRA seemed to be unfamiliar to many physicians) only left me angrier and more confused and, worst of all, ashamed.

Neither of my parents was comfortable confronting physicians. Like many of their Depression Era generation, they revered doctors and rarely questioned their judgments or treatment plans. The doctors and nurses themselves seemed uncomfortable when presented with a child with my symptoms, and were often less than compassionate. One nurse I remember told me sternly to “stop being a baby” for crying when presented with yet another blood draw by a needle that looked as big as my arm.

Once we found a doctor who was able to identify the JRA and prescribe a course of Solgenol injections, a very new medicine at the time used to slow down the body’s auto-immune response, my parents were relieved and placed all their faith in the one doctor who seemed to know what was happening to me.

The weekly injections helped my disorder and the medicine slowed the progression of the disease. However, by then many of my joints were already deformed and no medicine could correct that. As a result, I looked different, walked with a limp, could not run or play physical sports, and overall, stood out to my peers as a “weirdo.”

At times my mother would cry when she had to put on my socks and shoes for me in the morning because my fingers would not uncurl. The playground insults that resulted from my condition: “limping lizard,” “witch’s fingers”—and my mother’s overt grief about my condition, led me to feel somehow responsible for the sorrow and the medical expenses that accrued as well as the cruelty I encountered at school.

Although often using my disease as a way to get out of school or chores, over time I learned to hide my deformities in public, and would sometimes fly into a rage if anyone dared mention it outside the family. I was, to say the least, greatly conflicted; still, in a perverse sort of way, I felt a sort of enjoyment in the “status” it gave me as “different,” and “troubled.”

Over the years, the Solgenol injections lost effectiveness, and I was on so many different medications I lost count. More importantly,

my psychological defenses for coping with the pain and continuing degeneration (which is inevitable with JRA) were not healthy. I felt an unending anger at God, at the world but most of all, at myself for being “abnormal,” for not fitting in. I was rebellious, often in trouble in school; I experimented at length with drugs and flirted with suicide. In retrospect, I know I was punishing myself and those who loved me and feared for me by engaging in these behaviors. As both a teen and a young adult I would deny the disease, and put off taking my medication until I could barely walk. I felt deeply sorry for myself but would not allow anyone else to speak of it or offer comfort. The self-hatred was more than obvious, but it was not until I entered psychotherapy during graduate school that I slowly began to unravel some of the horrible binds I had put myself in.

My therapist, an incredibly gentle, patient, and completely honest woman, helped me see how I still blamed myself for being deformed, for needing medication, for the family’s medical expenses, for needing help with difficult physical activities, and for feeling too ashamed to ask for that help. Although not a “Buddhist” psychologist, she helped me see the cycle of suffering I had created for myself, by alternately denying reality and raging against the fact that it would not change.

Therapy also showed me that after a lifetime of being at war with myself the neurochemicals in my brain that normally would help me feel a sense of calm and well-being were absolutely depleted. The deep feelings of depression and self-hate were not just my old teen drama, but a very real physiological condition that I now understand often accompanies chronic illness and pain.

Therapy and medications were helpful, but it was not until I began exploring the practice of Zen meditation that I was able to put my “suffering” into a completely different perspective. Through the quiet of just sitting, attending to my breathing rather than all the busy thoughts in my head, I found I could have moments of peace in my mind. Reading some of the teachings of Zen, I learned that I was creating much of my own inner turmoil by piling suffering upon suffering in the form of the hate and shame and condemnation I felt toward my disease.

I must admit that I was not a quick learner. In fact, because it is impossible for me to sit in the traditional postures of lotus or even half lotus, I often ran away from the meditation hall because of that same

old shame before I realized that perfect, stone-Buddha posture is not what meditation is about.

With a good teacher and a supportive meditation sangha—a community of people who practice and study meditation—I slowly learned that meditation is not a curative; doing it “right” would not make my pain and suffering disappear. Rather, Zen meditation is about not adding to the suffering that is inevitable in all our lives, especially if we refuse to accept life on its own terms. Zen is about learning to experience one’s body and mind completely in the present moment, noting the various thoughts and feelings that arise as you sit quietly breathing, on a cushion or a chair or even lying down, but not grabbing those thoughts and running with them, tripping yourself up in fears for the future, regrets from the past, or rages at the present. The meditation that has helped me cope in healthier ways with the facts of my disease is a loving meditation, devoted to living fully, joyfully in the present, breathing deeply, watching how frantic my mind can be about absolutely nothing, causing me to miss what is right before me, right now. The joy I speak of is not that of permanent bliss; rather, it is the feeling of peaceful acceptance of life just as it is.

Although a daily practice meditation of at least 20-30 minutes each day is recommended by every teaching I have encountered, I do not practice in this traditional way every day. At least two or three days each week I practice with the sangha at the dharma hall, sitting on a cushion or a chair, following my breath, bowing, and chanting with the group according to our established schedule. When I am at home or at my office, I have a rocking chair at each place, and a small foot stool. I sit with these supports for anywhere from ten to twenty minutes, depending on my schedule, and gently rock as I follow my breath and watch my thoughts flow in and out of my mind.

Sometimes I find that I get caught up in those thoughts, follow them like a story, a daydream or a problem to be solved. When I catch myself in this process, I try to “unhook” myself from the thought and return my focus to my breath, to whatever is happening in my body. Am I tense, afraid, tired, or hungry? I label these thoughts and put them aside for later if they truly need attending to, then return to following my breath. I find this short, informal practice particularly helpful at work. I feel centered, more grounded and ready to be fully present with my next client.

There is a saying I have heard and often repeat to myself: pain is inevitable, suffering is optional. As bodies and minds that eventually deteriorate, sicken, and die, we cannot escape pain. Nor, given our mental and emotional abilities to love, hate, fear, and desire can we escape the psychological pain that is inevitable in all human relations.

But what we DO with that pain, whether we let it grab us by the nose so that we are pulled here and there, with no peace, no cessation of fear, desire, confusion, and pain, or whether we let all those feelings arise, without grasping or pushing them away, simply letting them be and move on, as they will, like clouds in a vast sky—that is what will determine the extent of our suffering.

Returning to my opening remarks in this essay: despite all my years of training as a psychotherapist and as a Zen student (I recently received Lay Entrustment, certification from my teacher to be a Zen teacher), I was still in an unconscious state of denial that my parents would ever leave me. For all of my fifty-three years they had been together, in my childhood home, always there to welcome me “home,” to take my phone calls, commiserate with my sadness, and celebrate my happiness. Despite their aging and my father’s bouts with cancer of the jaw, they remained fixed in my mind as somehow invulnerable. After all, they did the *New York Times* crossword puzzle every day “to keep [their] minds active.” They traveled throughout Great Britain and Ireland in their late 70s, played bridge and volunteered at hospitals and a raptor rehabilitation center (my father loved caring for and photographing all birds, especial large birds of prey). They swore they were always “fine” and needed no assistance, even as they approached their late 80s.

Then, last year in July, my mother suffered a terrible fall, and my father fell trying to help her. They were each too frail to help each other. They lay on the floor, out of reach of the phone, going in and out of consciousness for four days before neighbors discovered them (my siblings and I all lived out of state).

The damage this did to their bodies and my mother’s mind was profound. I have sat with friends as they watched their parents die. I have held a friend’s hand as she died of cancer. But to see my parents so helpless, confused, my father unable to breathe without a ventilator and my mother descending rapidly into severe Alzheimer’s, was a kind of suffering I never imagined for myself or my family.

In this book I have interviewed people who have cared for their ill spouses or dying parents, but never did I realize the depth of my own fear of this ever happening to me. Looking back, the words of the wonderful people who told me their stories for this book seemed to have been preparing me for what was to come. And the love and support of my teacher and sangha has enabled me to accept the reality of sorrowful loss without it breaking me completely.

I flew to St. Louis several times during the year as my father slowly died at home with the support of hospice. I was able to sit with him, read to him, and finally meditate with him as he silently did his own prayer with his rosary.

Meditation takes many forms in many other faiths, often through repetitive prayer. My father was a devout Catholic and typically prayed the full five decades of the rosary daily. I was not there the day he died, but I know that through those moments of quiet meditation with each other, I was able to feel the pain of losing him, without the added suffering of hysterical denial and fear.

My mother continues to struggle with severe symptoms of Alzheimer's. My youngest sister, Paddy and her husband, Rick, moved from California to the family home in St. Louis to care for her. They are models of true compassion and love, despite the daily frustrations of having to care for a mother as one would for a small (and often very angry) child. Like bodhisattvas, enlightened beings who return to this world to help others become free of suffering, they help my mother through her fears, hallucinations, anger and sorrow.

Originally I wanted to write this book to give others hope that despite chronic illness and pain, there are options to how one learns to accept suffering. I did not know how much the powerful stories of love and courage you're about to read would help me through the most difficult losses I have ever experienced. It is my hope that the voices here will lead others, too, to the profound, loving, and most of all, joyful acceptance of life on its own terms.

NW: After I had completed this article, my mother passed away on June 2, 2011. She died from a stroke during sleep just two days prior to the first anniversary of my father's death. After 58 years together, I believe she did not care to live another year without him. They both live on in my heart and I will always miss them.



Norman Fischer

Working With the Chronically Ill

Norman is an author, poet, and priest. He makes presentations worldwide, including an appearance on the Oprah Winfrey show. For many years he has taught at the San Francisco Zen Center, the oldest and largest of the new Buddhist organizations in the West, where he served as Co-Abbot from 1995-2000.

He is presently a Senior Dharma Teacher there, as well as the founder and spiritual director of the Everyday Zen Foundation, an organization dedicated to adapting Zen Buddhist teachings to Western culture in an accessible and adaptable way.

A person of unusually wide-ranging interests, he is known for the eclecticism, openness, warmth, and common sense of his Zen teaching, and for his willingness to let go of everything, including Zen, as a dogmatic system of beliefs. His chief interests, in addition to poetry and traditional Zen and Buddhist teachings, are the adaptation of Zen meditation and understanding to the worlds of business, law,

conflict resolution, interreligious dialogue (particularly with Jewish and Catholic faiths), the world of technology, and the care of the dying (he has for many years been a teacher with, and is emeritus chair of the board, of the Zen Hospice Project).

Q. When did you begin practicing Zen, Norman?

A. I began my Zen practice in 1970. As a young man in college, I was interested in the nature of reality. I thought meditation would be a good way to investigate reality. When I found out about the practice, I immediately devoted myself to it.

I went to train in a Zen monastery in America from 1976 to 1981. In 1981 I moved to a Zen temple that was a semi-monastic enclosure. I lived there from 1981 until 2000. I was ordained as a priest in 1980. Between 1995 and 2000 I was abbot of San Francisco Zen Center. I have spent my whole life in Zen training temples with daily meditation practice and frequent Zen retreats. I received Dharma transmission (the complete acknowledgement of the understanding of the teachings of Buddha) from my teacher, Mel Weitzman. Dharma transmission is a very special ceremony giving a priest certain authority and empowerment.

After my term of office as abbot was over, I retired from the Zen center and started the Everyday Zen Foundation. Everyday Zen is a large umbrella organization that includes many different Zen groups up and down the Pacific Coast from Canada to Mexico, as well as a number of other projects. Everyday Zen involves the application of meditation to various aspects of American life, including the work of conflict resolution professionals, people in the technology industry, and people caring for the dying. So, briefly, that is that what I have been doing for the past thirty-five to forty years or so, as well as raising a family.

Q. Have you worked with many health compromised students?

A. People who have been practicing Zen with me have had illnesses. One of the priests I ordained, a man I was very close with, was Michael Sawyer, a painter and full-time Zen practitioner. He suffered from Parkinson's disease for twenty-five years. In many ways, he made the Parkinson's disease itself, his experience of

it, the centerpiece of his spiritual journey. It was always a very moving thing to hear him speak about his Parkinson's, although toward the end of his life he lost the ability to speak. With Michael I really got a crash course in Parkinson's disease and how meditation and mindfulness practice can have a significant impact on one's experience with that disease.

When I have worked in groups, it has been primarily with dying people. I have also worked with people who have cancer and many other maladies, as well as with the caretakers of dying people.

You know, it is very complicated. With physical pain there are so many dimensions and there are so many sources of sensations involved with the experience of pain. There are the psychological and personal feelings that go along with it that actually make it more painful, more distressful. It is all of this that we must work within our meditation practice.

Practitioners who have struggled with chronic disease often think: "If I just practice hard enough or better enough I should be able to rid myself of this pain."

That is the trick: to remember that the goal here is not to make the pain go away or the difficulty go away; although to be sure sometimes there is relief from the pain as a result of meditation practice.

How do we manage it?

How do we live with what we have?

These are important questions.

Q. When you work with groups, is there any particular form of meditation that you teach or instructions on a particular area around the issue of pain?

A. I use many different techniques. Typically I will tailor something to an individual's needs or to the needs of the group. The fundamental meditation that I always come back to and that I think is the most helpful is sitting with the sensations of the body and with the breath. Being present with whatever is there, whether pleasant or unpleasant sensations, whatever thoughts, whatever feelings may arise. Staying with these sensations of the body whatever else arises.

This is very counter-intuitive, one would naturally think—"now how is that going to help me?" But the fact is that the willingness to actually be present, without hating what you are feeling or trying to make it go or stay (if it is pleasant) and just allowing something to come, allowing something to go: that is the most powerful, the most fundamental meditation. I always return to that. That is basic. I think it is the most profound principle not only of Zen meditation but of all Buddhist meditations. We always return to that.

There is a wonderful, colorful phrase in Zen:

"You don't put another head on top of your own."

The first head is: *you have a pain*. For example, with rheumatoid arthritis it is pain in the joints. That is one head. Putting a head on top of your head is to say:

"Oh I hate this pain. This pain is bad and I shouldn't have to feel it."

"Why won't it go away?"

"What did I ever do to deserve this?"

"How come nobody else has this pain?"

All of that actually becomes, in many ways, more painful, or at least as painful, as the original pain. The idea is this: can you accept and be present with the pain and take away that second head that you put on top? If you can, then you just have the original head, and life may become much more bearable and sometimes quite beautiful.

Q. I must admit I often question the beauty part. How do you make sense of the contradiction of beauty and pain?

A. In a way—you do not even have the disease. You have a set of sensations in the body. The disease is a convenient label that is put on that set of sensations so we may have a common language; a word to symbolize all that we mean when we discuss these symptoms.

In a beauty and health obsessed society like the one we live in, it is very difficult to feel you are not in the swim of things, that there is something different about you or something wrong with you. The isolation and loneliness of that is really one of the most painful aspects of chronic illness. And that pain is very much self-imposed, although at the time you do need support.



Q. A myth many people believe is that the lotus or half lotus positions are the only way to meditate. If I can't sit with my legs crossed, how can I still meditate?

A. When there are meditation instructions given, very often the traditional postures of sitting the lotus or half-lotus positions are the ones taught the most. However, meditation can be done in a number of ways:

- It can be done by slowly walking (“kinhin”) (see above).
- It can be done sitting a chair.
- It can be done lying down.

There are people who have spinal issues. They may not be able to lengthen the spine. But they can do that as much as it is comfortable for them and then pay attention to the breathing. We are always breathing. There are people who have compromised breathing. But we are all breathing to some extent with whatever degree of freedom we can manage. Paying attention to the breathing and to the sensations of the body regardless of the posture is the point. When you have issues with your body one extreme is:

Oh no! My body is a mess.

I am wounded.

I am not as good as other people.

The other extreme is:

It is all in my head.

I ought to be able to sit up perfectly straight in the lotus posture no matter what is wrong with me.

I will make myself do that.”

When you have physical issues you have to explore the edge of your abilities. You really must make an effort to sit up straight. If it is difficult for you because of your condition you have to pay attention to that. You have to ask yourself:

What is my edge?

What are the physical limitations of my body?

What is being influenced by fear rather than pain?

Where can I be open and straight in the body as much as possible?

Where am I going too far and imposing something on myself?

We want to find our own unique way, depending on our condition, to open our body, to make the body open and uplifted.

We need to experiment at times to find our answers. We want the body to be uplifted, lengthened, and stretched from the inside. We want the spirit to open up in the body. We all have to explore the edge of how to do that for ourselves.

Q. You have often mentioned in your talks the importance of taking a few deep breaths before you give into the discomfort and move. Can you say some more about that?

A. That is a very important and profound point. There needs to be courage to be able to be there with it. The natural reaction is:

I cannot bear this.

I need something to distract me from the pain.

It is so important to have the courage realistically and honestly, with lots of kindness to ourselves, to do what we need to do for ourselves and actually be with the sensations in the body as they are.

Q. So what you are saying is rather than doing what I usually do, trying to move away from the pain—it is more beneficial to try and experience the pain consciously?

A. Yes, some engagement is the thing. Are we willing to engage the sensations of the body that may be very difficult? If we don't

engage, if we abdicate our bodies, then things get a lot worse. In reality we are in a constant engagement, a constant dance with our illness.

It makes it quite creative and quite challenging. An illness can be an incredible task of courage and creativity. No doubt it is very difficult and tough in a lot of dimensions, as we have been saying.

If you are willing to engage it, it becomes very noble. Some of the most noble and courageous people I know are people who have chronic illnesses who have had to cope with them. It has made their lives definitely tough but also quite noble and strong because they have had so much to deal with.

Q. Are you saying the best way to meditate is simply opening up, focusing on your breath, being in that moment, and experiencing your body—whatever it is, exactly as it is in that moment? Is that the only “correct” thing about meditation?

A. Yes, exactly. Unfortunately that is what we often do not allow ourselves to do. We say there is a “correct” way to do this and what follows is, “I guess I can’t do it because I have Parkinson’s or I’ve got rheumatism or I’ve got this or that. I guess I am not able to do it correctly.” And that defeats the essential point of Zazen.

Q. If we may switch from the physical to the more mental or cognitive aspects of meditation—often people struggle with intrusive thoughts as they sit and breathe. How would you address this issue?

A. In Zen meditation, particularly in the style of Zen we do, Soto Zen the goal is not to make the mind blank and free of all thoughts. Meditation is not a blankness of mind. The effort is rather to allow everything in, to come and go whether it is a thought or a sensation or an emotion. As a thought comes:

We allow it to be there.

We acknowledge that it is there.

And we return to our breath.

This is not what we usually do. What we usually do when a thought comes into the mind is to seize on it or we let it seize on us.

The thought pushes us around. It, in turn, creates so many other

thoughts. The mind goes around and around and around and so on.

The goal in meditation is not to make the mind free of thought. Rather, if we wish to say meditation has a goal at all, it is to allow thoughts to come and go without getting caught in them. That is a subtle difference, but it is really important. If you think you are supposed to have no thoughts, you are going to be frustrated. Thoughts come and go all the time. As this happens you will think you are not doing it correctly. You have to realize that no, that is normal.

On the other hand, if you just sit there and ruminate, you are not going to get the goodness that is possible from meditation. What you want to do is bear witness to thoughts as they arise. You can say to yourself:

"Thank you very much. I recognize that thought is there. Now, I will see you later. I am going back to my breath."

"Oops. There is another thought. OK. Thank you very much. I understand that thought is there. Isn't that nice? Very interesting. Back to the breath."

"Oops. There is another one."

That way, very patiently you just stay with your practice. Little by little, the mind will be trained to get caught less on thoughts and there will be less agitation in thinking. Thoughts will come and go and it will be OK.

Q. I have heard you say many times during your talks on Zen meditation that thoughts and emotions are like clouds. They pass through the sky of your mind if you just allow them to pass. Can you say more about that?

A. There is another great Chinese saying about this.

"The blue sky does not hinder the white clouds passing by."

It is just like you are saying. The white clouds are the thoughts that pass by. They can pass by the blue sky that remains constant, allowing the thoughts to pass.

The trouble with us most of the time when we are not meditating is that there is no blue sky. There is just the sense of our being stuck with many thoughts.

When you meditate, when you return to the breath and the body, you make that commitment to yourself. What you are doing is creating



the spacious blue sky in which the thoughts can come and go. When you do not latch onto them, they are actually not a problem.

- Q. I have found that often thoughts involve memory or future planning. In a sense, when you latch onto those thoughts you are no longer in the present moment, you are in places that don't even exist. When you return to the present, you see that they are only thoughts or memories—no “real” place at all, correct?**
- A. There is a surprisingly healing power in being present in the way you are speaking of. It is very counter-intuitive, but experience bears it out.
- Q. Often when in meditation, I begin to feel very much in balance, very much in the moment, without getting too caught up in the euphoria that usually does come; when I first realize, “Oh—I am doing it!” It feels so right and balanced there. Then, suddenly, I am no longer in meditation. I am outside, observing myself, and once again I am out of balance. What am I doing wrong? What am I failing at—that I am not still in that place?**
- A. The project I started after I resigned from the Zen center is called Everyday Zen, which is a phrase of the tradition—everyday practice, everyday mind.

The most important part of Zen practice is bringing the mind that we cultivated in meditation to our everyday experience.

The thing about meditation is that—although it may seem hard—it is actually much easier than we think. In meditation, we simplify our lives. There is nothing else going on but just sitting there and being with ourselves.

That is a very good situation for training our minds. It is much more complicated to be present in all the ways we have been talking about in daily life, when we get hooked in a million ways to our usual habits, ways of thinking, and ways of being.

Zen practice—and I think this is true of every authentic school of meditation—wants us to go beyond just finding some peace and release in meditation to finding a different way of being in our lives all the time.

Meditation is a way of training us to do that. So what we want to do then is find a way to let thoughts come and go, not getting hooked in old patterns and old routines, which we can do most easily on the cushion. We want to then be able to extend this into our daily lives.

What if we allowed our senses to take in and truly see and hear and smell and feel everything we experience while on a walk? What if we stop dreaming and just cook a meal? If we are cutting vegetables, can we stop just wanting to get it over with and think about how it feels to be:

Standing here right now?

To be working in this moment?

To be cutting this vegetable?

And now this one?

You can talk to or listen to another person, with a powerful sense of being present. Certainly in a therapeutic situation, the more you are able to really be present with the person as you are listening and speaking, the more you will be able to offer them something.

In every situation we are in, we can always bring that awareness of the present moment to wherever we are, whatever we are doing. It will always be healing and helpful. We can, if we choose, use everything in our lives as meditation objects.

Working in the kitchen

Walking down the street

Listening to someone

Helping someone work

Our work on the cushion, which we hope is regular and disciplined, or to whatever extent we can make it, we then carry over into everyday life. Little by little, we begin to live a life of awareness and honesty about what is actually there. That is going to require us to stop wishing and wanting and trying to get rid of certain things, or hold on to other things. Meditation can help us say, "OK, I want to live my life as it actually is."

If I am insane right now, I am insane right now. Let me live with that. If I am happy right now, let me be happy. Let me live with that.

I am willing to live with whatever comes. If I am able to live with whatever comes, then I can have a much happier life.

There is nothing worse than having many things going on and you do not want to be there. You can't make it go away. It is there and you are miserable because you do not want it to be there. That is usually what happens when you have an illness, right?

You are actively miserable. You have put a head on top of your own head. You have the illness and now you are miserable because all you want is for that illness to go away. We have to cut through that mind and be willing to be present. When that happens, magic happens.

Q. That is very true in my psychotherapy practice. I think I am never as present in the moment as when I am really listening to someone's experience. Yet, I sometimes find later that it is difficult to listen fully to my husband or my friends. If I cannot pay attention to them, what is the point of my work, either in meditation or with my patients?

A. What you are pointing out is something that will resonate with many people. Maybe I can do this at work and maybe I can do this with my friends, but it is harder at home. It is harder when I am alone. Little by little, we can do it. Little by little, we can extend our mindfulness. Also important in what you said is how healing compassion can be. You are lucky to have a job like the one you have where you can intensely be present with loving concern for others. How healing that must be for you to be able to do that.

I think anybody who is suffering from an illness potentially has the capacity to be more compassionate with the people in his or her life.

There is nothing more moving than when someone who is ill says to you:

And how are you feeling?

How is your life?

What is going on with you?

When you know they have so much that they are struggling with, you find that it is very moving when you hear it. Also, from their point of view, it is very healing for them to see compassionate concern for others. Compassion itself is medicine. It is healing to be compassionate for ourselves and for others.

Q. Again, to change subjects a bit, I have been asked, “do you have to wear those robes?” If they are Christian, isn’t this against their faith? How can one meditate if they believe in Jesus or Mohammad?

A. No. You do not have to wear robes. Really, as far as I have seen, it doesn’t make any difference whether you have Christian faith or Jewish faith or faith in Islam or you have no faith in anything religious.

If you are willing to do the practice, if you are willing to pay attention to your experience, you will probably be helped quite a bit.

If you do have a powerful belief system, the likelihood is that it will enhance and make you feel more deeply about what you believe. You will see dimensions to your beliefs that you did not see before. Many people who practice with the Everyday Zen groups do have very active Christian or Jewish practices. I do not think there is any conflict or contradiction.

I am sure you can find Christian believers or Jews who would say practicing meditation is against their belief system and is not allowed. I don’t mean to say that there are many people who feel that way. But there are also many, many believing Christians and those of other faiths who find meditation beneficial.

I have presented meditation to many thousands of people. Maybe to some extent my audiences are self-selected so the ones who hate meditation don’t show up. Usually people are happy to learn about meditation. They may not choose to practice it regularly but they always find it interesting and useful. Only twice have people who heard what I had

to say responded with: “Oh no, that is terrible. I would never do that.”

In both cases they were Christians. One was a very strong Catholic. One was a Baptist. They both said the same thing: “Oh no, we do not want to sit still in silence because that is how the Devil gets in. We are just opening ourselves up to the Devil who will sneak in and take over our minds.”

I thought to myself, “Gee, it must be a tough life if you feel like you have to be wary when you are alone with yourself for fear that someone will take over your self.”

I would not want to feel that way about my life. I would want to feel like when I am alone and quiet, God would take over. That goodness would be naturally what’s inside of me. Not the devil. I may also have all sorts of odd or bad impulses inside me. But this isn’t the devil.

I have done a lot of interfaith work, ecumenical work and practice in monasteries and synagogues. I am very interested in other traditions and recognize their tremendous power and goodness.

Every religion has something to offer that is unique. Every religion has unique gifts. I really appreciate the gifts of all the traditions.

Q. People who meditate are often asked, “Do I need to take a course on how to meditate? Does it make a difference if I meditate with other people? Should I meditate alone? How do people learn to do it?”

A. There are lots and lots of meditation groups these days. If somebody gets creative on Google you can find out about a number of meditation groups. I don’t care where you live, I guarantee you there is some sort of meditation group. It may be hard to find, but it is there. Most groups offer some type of basic instruction.

There are also countless books that offer written meditation instructions, not to mention websites with audio files, including my own Everyday Zen website, which offers all kinds of meditation instructions and even guided meditations that you can use for practice.

It is not hard to learn how to meditate. There are places that offer organized courses rather than simply meditation instruction. They may have a five-week course or a three-week course. Mostly those things are worthwhile as well, but I do not think they are necessary to meditate. I think most people who meditate, meditate at home on their

own. That is what I do now that I no longer live in the temple.

It is also a good idea to meditate with others. I think it really helps. If you can find a group in your area that you feel comfortable with, then go sit with the group maybe once a week or however often they meet or however often it is convenient for you. The rest of the time you can meditate alone. It is really important to have some connection to other people who are meditating from time to time so that there is a feedback loop in your meditation. The feedback doesn't necessarily have to be verbal instructions. It is just being around other people, seeing how they are and how they talk about their meditation practice in a casual way.

This in itself can be very instructive. So I think it is really useful to practice with others who are meditating. If it is the case that for some reason you can't get to a group or you can't find a group in your area, then yes, you can meditate alone. I would say seek guidance from websites and audio files.

Again, the Everyday Zen website has hundreds and hundreds of free audio files on meditation-related subjects that you can access. There are numerous other websites that you can access. Even if you are unable to leave the house, there are lots of ways you can still get guidance and participate with others through the computer.

If you are able to do it, I think it is very valuable to do retreats for one day or multiple-day retreats. There are always people who come to meditation places with chronic illnesses. The only important thing is that when you apply for a retreat let people know what you need to accommodate your limitations. Some examples may be:

I will need a chair

I will need a modified schedule

I will need a certain diet (such as for allergies or diabetes)

I am not sure what I will need but I know I'll need help

If you do that, the people who are running the retreat will know what is going on and help you find what you need. I can't imagine that there are very many groups that would say no—that if you have these limitations we do not want you to come to the retreat. Most groups these days are quite friendly to accommodating special needs or can offer you all kinds of guidance.

The best way to begin is to get some instructions from a book or in person, and begin to do daily meditations, find a group, and begin to

attend once a week or once a month or whatever you can do.

Eventually, if you really like the practice and if it begins to be meaningful for you, seek out a retreat you can go to. If you do all of these things, you are in a very transformative process that has the potential to change your chronic illness from an unmitigated tragedy into a tough, but noble journey.

In a retreat, people with chronic illness often have the very opposite experience than they expect. The truth is that if you show up somewhere with a chronic illness, especially to a meditation center where people are trying to practice compassion, you are giving them a good chance to practice that compassion. Truthfully, you are helping them out.

Usually people with chronic illness say:

Oh my goodness; I better not go anywhere.

I am going to be a bother to people. I am going to be a burden to people.

I don't want others to feel they have to take care of me.

If I can't do the schedule like everyone else, I shouldn't be there."

But it is just the opposite. You are giving people a chance to feel compassion and have the joy of helping someone out. So, you are a real treasure for them.

Meditation centers are supposed to be places where the practice is all about compassion, all about kindness. If you were to go to a place where they weren't compassionate and they weren't kind that would not be a good place to practice.

Q. Some people feel that if they are going to practice meditation they can't take medicine; that they must respect the precept: "I cannot intoxicate my body or my mind." Therefore, they cannot take medication to relieve their symptoms or their pain. How would you address this?

A. I think the important issue is how the substance itself that comes into your body works with your meditation practice. Buddhism is about the middle way. Is your practice about medicine and taking more and more medicine? Or should I be able to do this myself without any medicine? The middle way is between those two things. There are two parts to everything we ingest into our system, every medication our body reacts to and works with that substance, most of which is not conscious.

Our state of mind influences that dynamic. The medications also influence our state of mind. It is a matter of being thoughtful, responsive, and sensitive to the interactions of the medication.

The body is always changing. The illness is always changing—getting better or getting worse. The medications constantly need to be adjusted. You really need a medical practitioner who is willing to talk with you about these things—someone who is also sensitive to your other needs, such as your meditation practice. You also need to pay attention to how you are feeling and your changing states of mind, perhaps keeping a “How I am feeling?” journal that you can go back to and look at so you know what is going on with your state of mind, your state of body under different medications and their dosages.

That becomes a very big factor especially in the case of Parkinson’s. There is a whole dialogue of the medications and how they make the body feel—sometimes better, sometimes worse. It gets very complicated, as all Parkinson’s sufferers and other people with chronic illness know. You just have to be patient and don’t make any assumptions. Keep looking. Keep asking yourself:

What am I taking now? Does it affect my mindfulness?

How does it affect both mental and physical function?

What is the balance between “tolerable” vs. “intolerable” pain?

That conversation is ongoing. It is not as if there is a simple way of figuring it all out so everything goes smoothly. No. There are problems, as everyone knows who has been in this situation. You do your best to minimize the problems and be thoughtful about what is going on. Sometimes there are wonderful breakthroughs. I was talking with a person yesterday who had a heartwarming story. After 10 years of suffering with an illness, with nothing working and no medications helping. Finally she said to the doctor: “You know what makes sense to me. We should try this.”

The doctor said, “Well, OK.”

In this way, he was giving back to her the control of her body, of her illness. It completely, at least for the moment, has turned her around. She is in a wonderful period of low symptoms, which may end up being permanent. Sometimes things like that happen after a long, long time. Sometimes they last. Sometimes they don’t. It is a constant adjustment. Then again, what in life isn’t a constant adjustment? We are getting older. Things are changing. It is always like that.

Q. Regarding the use of meditation in coping with pain and illness, many medical pain clinics now use guided imagery as a way of relaxing the patient and hopefully giving some symptom relief. How does guided imagery differ from meditation, or does it?

A. I wouldn't say that they differ necessarily. There are many forms of meditation. The style of just being present is a basic, fundamental style and the characteristic of Soto Zen, the Zen of our first teacher in the U.S., Shuryu Suzuki Roshi. It is the practice of shikintaza, or "just sitting"; just breathing and letting thoughts and sensations come and go as we discussed earlier, without clinging to any one idea or feeling. It is just one form of meditation. Guided imagery is another form of meditation. Earlier we talked at length about the practice of just being present with the breath. Guided imagery usually involves a facilitator who gives verbal instructions while you are meditating, such as:

Imagine this sound.

Imagine this scene.

Imagine this scent.

Feel this sensation.

Visualize this shape.

See this color.

You try to imagine it and reproduce it in your mind. That is a very different technique from the meditation we are discussing. However, all of these things are useful. I think one should practice whatever is most helpful.

Q. Is it possible to do a "quickie" meditation, a meditation that is about one to five minutes long? Is that is effective?

A. Absolutely. In fact, a practice I often encourage people to do is a three-breath meditation. Sitting, standing—wherever you happen to be—stop and take three conscious breaths.

BREATHING IN.

BREATHING OUT.

BREATHING IN.

I encourage that and think it can be wonderful. The important thing here though is to recognize that if you say, “Because I am so busy, the only thing I have time for is this quickie meditation” then, the chances are overwhelming that you are fooling yourself. No one is that busy.

In fact, I always tell people, “Meditation saves you time. You don’t have time not to meditate.”

What one is busy with when not meditating is all the messes and mix-ups that occur because we are not mindful: “I am busy. I do not have time to meditate because I cleaning up the mess I made when I dropped my coffee all over the floor because I was rushing and tired, which would, perhaps, not have happened if I had meditated.”

If you analyze your day, you are putting out fires, many of which would not have started in the beginning if you were more mindful.

So, I just don’t buy it when someone says “I am too busy to meditate.”

So—quickie meditation—absolutely. Do it whenever you want to. Do it many times a day. But don’t tell yourself, “I need a quickie meditation because I don’t have time to meditate.” I think you are probably fooling yourself if you tell yourself that.

Q. How does one quiet the mind when a disease such as Parkinson’s makes it difficult to meditate because there are tremors?

A. With Parkinson’s one tends to have tremors. The only way you can mediate is to be present with the tremors to the best of your ability. It is going to be frustrating if you believe you must stop the tremors before you can quiet the mind. The characteristic of the tremor is that it is not just in the body. Parkinson’s is a neurological disease that involves the brain. When you are in tremor, it means that the mind is in tremor along with the body. By definition, a mind that is in tremor is not a mind that is quiet.

What you have to do is, to the best of your ability, stay with your breath and ride the tremor through with full presence. Insofar as you can do that, it very likely has the effect of minimizing the tremor, bringing the series of tremors to a conclusion more quickly or having a little of the edge taken off the tremor.

Parkinson’s is a very powerful disease. I fully recognize that it may be that just being with the tremor will not change the tremor in any

way. My friend Michael Sawyer was really marvelous at being present with his tremors; being present when his body was frozen. It is an ever-changing situation with Parkinson's. As every day goes by, you are on different medications, which are in different stages of being absorbed in the blood stream. You look for those times when you could be quieter and you capitalize on those. It is quite an endeavor. I understand that.

Q. Some people say they meditate better with music in the background rather than simply sitting still, breathing. Do you have any advice on that?

A. A lot of times, when people recommend music it is because they are thinking of meditation as a specific kind of calmness of peacefulness. The kind of meditation that I am talking about is not that. It is really being present with just what is. We are not advocating a type of meditation that gives you a break from your illness and then back to the tragedy; rather, a form of meditation that gives you a whole new way of being present with your condition, whatever it may be. I am not proposing that meditation is going to be peaceful and calm. No. What I am advocating is this: be present with whatever is there. That is ultimately the most peaceful thing. I advocate being willing to get out of it. Ultimately, this is the most powerful healing.

All of my meditation teaching and all my ideas about meditation have to do with being present without any music or without any extras. Having said that, if someone said: "I really love my meditation. It is so peaceful and nice and I really love listening to music." I say, "Great. More power to you." I do not have a problem with that. I just want to be clear that what you and I have been talking about is something other than that.

Q. How much time per day is necessary for meditation?

A. I always tell people, if you want to establish a daily meditation practice (which I think is a really good idea), twenty or thirty minutes a day is good. Occasional meditation when you feel like it probably doesn't help that much. First thing in the morning I think is the best time. Certainly you can practice more if you like. I think it is probably good to not sit for more than thirty minutes.

You can then walk for ten minutes and sit again if you like. But a twenty-thirty minute meditation is a good enough time to begin to see some changes in your mind, in your heart and in your life.

Q. How can I make meditation a part of my daily routine?

A. The way to do it is on the night before, make sure to set the intention: “Tomorrow morning I am going to get up and meditate. I really want to do that and I will do that.” As you are falling asleep, review that thought. The next morning if you listen to the alarm clock or the rooster crowing before dawn, get up before you have a chance to think about it or do anything or have your tea or coffee. Go right to your meditation place and start sitting. I think that is the best way to put meditation into a daily routine. Once the day gets busy it is more difficult to feel you have time for meditation.

I would say—start that way. Then you can do the practice that we mentioned earlier— the three-breath practice. Do that several times during the day. In the middle of the day when you take a break for lunch, spend twenty minutes with peaceful walking up and down, just to return your mind to presence. If you were to do these things, you would really revolutionize your life and meditation would pervade your life. They are very simple things. They don’t take much time. But they make a big difference.

Q. Do you think regular meditation practice can stop the progression of a chronic disease?

A. If I could answer that question with something that would really work, wouldn’t that be great? I would go to all of the medical clinics all over the world and I would share this information. I would really do a lot of good for a lot of people. Unfortunately, I do not think there is the kind of answer you are seeking. In this whole conversation, we have been talking about ways to be engaged with Parkinson’s and other chronic diseases as they progress so as to minimize the psychological, spiritual, and physical damage and to make the illness itself a spiritual path, as my friend Michael Sawyer did so beautifully and nobly.

If I had a way of making the symptoms not do psychological, spiritual, and physical damage, and to make Parkinson's itself a spiritual path, I would be a magician. I am hoping that, if you have been as recently diagnosed as a year ago, we can cross our fingers and hope there will be some curing drugs coming before too long. That is very possible. Parkinson's as we all know is one of the diseases being worked on quite a bit, so there is every chance something positive will happen. Of course, they have been saying that for a long time and we can't count on that. We really have to make up our minds to live the life we have, as it is, as long as it remains as it is. I wish all of you with chronic illness the best of luck.

I am really convinced that having a chronic illness can be a spiritual path. If you look at it this way, it really changes the whole frame around the picture.

Q. How can people get in touch with you?

A. We have tons of information about meditation on our website: everydayzen.org. The website gives people support for their spiritual practice. It also has my schedule if you want to meet with me or come to a retreat. You can see how to do that by visiting the website. On the website are books, CDs, and many recordings of talks about meditation that are downloadable to your computer free of charge. You can make a donation if you like, but that is not necessary. You can download the talks onto your computer or put them on an iPod®.

NW: Thank you Norman, for sharing your experiences and insight with us today. To our readers, please look into Norman's website. He not only has talks and tapes about Zen and meditation, but has also written many books of poetry, as well as beautifully written books on his experiences as a mentor to teens, travels to Israel and Japan, and *Sailing Home*, an exploration of Homer's *Odyssey* as a metaphor for navigating through "life's perils and pitfalls."



A young, playful Masako



Ruth Ozeki

The Art of Living and Dying

Ruth Ozeki is a filmmaker and writer, the author of the internationally acclaimed novels *All Over Creation* and *My Year of Meats*. Her short fiction has appeared in a number of anthologies, and she is an occasional contributor to magazines and newspapers, including the *New York Times* Op-Ed page. Recently she collaborated on a young adult novel, *Click*, to benefit Amnesty International.

She is a long time meditator and student of Zen Buddhism, and she has recently been ordained as a priest in the Soto lineage of Suzuki Roshi through her teacher Zoketsu Norman Fischer, whose website, everydayzen.org, she edits. Her essay about taking care of her mother who suffered from Alzheimer's disease, entitled "The Art of Losing: On Writing, Dying, & Mom," written for *Shambhala Sun Magazine*, is included in the anthology Best Buddhist Writing of 2009.

Q. You have written a beautiful article titled "The Art of Losing: On Writing, Dying, and Mom," based on the Elizabeth Bishop poem "One Art." Will you please say what inspired you?

A. The article was a meditation on the process of care giving and losing someone I love. I was taking care of my mother, who was at the end of her life, but as her primary caregiver, I needed to take care of myself, too. I do this by writing. For me, that is what writing is all about. It's a way of exploring the most crucial aspects of my life. Writing is a parallel path to meditation in that sense.

Q. Both of your books, *My Year of Meats* and *All Over Creation*, portray some of the cultural struggles of Japanese-American women. That is your heritage as well. Will you say more about this?

A. Yes. My mother was Japanese and my dad was American. And although my ethnic and cultural heritage is a theme in the books, I've also been thinking about them as stories of illness. Both books have illness, in particular environmental illness, at the core, and it's interesting to look at the two books through this lens.

The two central characters in *My Year of Meats* face challenges around reproduction. One protagonist is a Japanese woman who is trying to get pregnant, but who suffers from bulimia, which has caused her to stop menstruating. The second protagonist is a half Japanese, half American woman who learns that she is a DES daughter. Her mother took Diethylstilbestrol (DES), which is a hormone that was prescribed to women to prevent miscarriages. The drug was later discovered to cause various reproductive deformities, as well as cancer, in the daughters and also the sons of the women who had taken it. Later tests also proved that the drug made no difference whatsoever in preventing miscarriages. It was never effective for that.

In *All Over Creation* the protagonist's father suffers from colon cancer, complicated by a chronic heart condition, and her mother has Alzheimer's. The wife of the neighboring farmer has had breast cancer and is unable to carry a pregnancy to term, due, they suspect, to groundwater contamination from chemical farm inputs. This concern with illness, death, and caretaking was reflective of my own experience at the time, taking care of my dad and my mom in the decade leading up to their deaths, but of course sickness, old age, and death are central issues in Buddhism, as well.

Q. What is your personal experience with the practice of Zen meditation? How did it help you through those difficult times?

- A. My dad died in 1988. I didn't have a serious meditation practice at that time. I started sitting in 1995, but I wasn't sitting regularly. This was in New York, and I was working a high-pressure job in television. I was drawn to meditation but never really understood how important it was. When my father's health began to fail, and I started taking care of him and my mother, I started feeling the need, the urgent need, to meditate. I needed it to keep myself centered and sane. The experience of taking care of my dying father made me realize that I just did not have a steady ground underneath my feet. I did not really have the stability and steadiness that I needed to take care of him and my mother properly. I felt huge remorse at that time.

I remember being on the East Coast, visiting one center after another, looking for a place where I could sit and receive meditation instruction, but I was unable to find a place that could accommodate the immensity of my grief. I remember walking into a meditation center. At the same time, in 1997, my mother had just been diagnosed with Alzheimer's disease. I knew that I was going to be the one taking care of her. I am an only child. One of the last things my father asked me to do was to take care of my mom. I realized then I was going to need some serious help and training to do this. That was when I got serious about meditating.

Learning to meditate regularly took a while. It takes some time to establish a practice, as well as to find the support and trust that you need from the other people you sit with. Also, you hopefully find a teacher with whom you can work.

During this time I migrated out to the West Coast and was fortunate enough to meet Norman Fischer, an ordained Zen priest and former abbot of the San Francisco Zen Center. At the same time I was able to find a group of wonderful practitioners to sit with. That was important for me. However much we may want to be independent and meditate on our own, it's truly helpful to have a group of people who are engaged in the practice as well. In 1999, my husband and I brought my mother out to live with us. She lived with us from 1999 until 2004,

when she died. It was during that time I wrote about a daughter who returns home to take care of her father who is dying.

Writing that story was a way for me to sit with, and practice with, all of the things that I felt I hadn't done well during my dad's death. It was a way of revisiting that time and going over it very carefully, trying to understand what it was that I was feeling.

Q. How has practicing Zen meditation made a difference in your approach to both loss and integrating loss into your daily life?

A. I've been able to relax a bit and start to see loss as change, as a necessary and inevitable part of life. I've made the commitment to sit every day and typically do that. Some days I miss, but generally my practice is to sit every day. I sit for about forty minutes but sometimes it's shorter. Sometimes it can be as little as ten minutes, allowing myself to experience whatever arises during that time. What is important for me is the idea that I purposely return to mindfulness with some kind of regularity. In this way, as I practice over and over again to the present moment—what develops is a sense of trust or self-confidence in just what is. I know that even if I mess up sometimes, if my mind is overly reactive, or if I'm sleepy or excited or depressed or joyful or angry, it doesn't really matter. Everything changes, and through the practice, I can experience a returning to the present.

Through that returning, I gradually become familiar and friendly with myself, with my Buddha nature, and I start to see loss for what it is, an essential part of life.

It is a funny kind of thing. I don't want to use the word faith because faith is a loaded word. Maybe the best words to describe the fruits of a meditative process are trust and self-confidence. I am going to be here, showing up for myself every day. I am worth this effort, and it is something that I CAN do, for both myself and others.

In a way, it is similar to the writing process, which I can describe in the same words. If you show up every day at your computer or at your desk with a pen in your hand, eventually your mind starts to trust you will be there, ready. When your mind starts to trust that you will be there and that you are showing up every day and that you are ready, then words start to come. Thoughts start to come that develop into stories.

In that sense it's a way of learning to trust yourself, trust that you will be there. No matter what happens, no matter what comes up—feelings of anger or grief or disappointment or elation or any of the vast range of emotions—you can sit through it, and with it, and be okay with it. That's true whether you are practicing meditation, which is really the practice of just sitting and being with what comes up in your mind without judging it, without evaluating it; just sitting with it and being okay with exactly who you are and what you are experiencing at that moment.

Of course, in writing there's that added step of recording the feelings and words that come. In meditation you experience them and release them, without clinging to them or wishing they were different. I suppose writing is another way of releasing thoughts and feelings as well. You are just doing it with an added step in there. They are similar in that sense.

Q. The writing process you speak of results in following those thoughts out to create what you want to communicate to others. In Zen you do not follow those out. You let them go. It sounds like you can do both.

A I think that's right. In zazen (sitting meditation, just breathing) thoughts arise, emotions arise, and you try not to “get stuck” on any one thing. At the same time, we all live creative lives. Our life is ultimately our creation, and any insights we have on the cushion we can “follow out” in our everyday lives. By encountering our thoughts and our emotions on the meditation cushion, we get to know them. We become very intimate with them. The same thoughts arise over and over again. The same emotions arise over and over again. We allow ourselves to deeply experience them. These thoughts and emotions are often the core of the stories we tell ourselves about ourselves and the world we live in; the way we define ourselves and our relationship to the world. When we come off the cushion we then are more equipped to engage in this creative act called our life.

We are able to engage with it in a much more intimate and present and creative way. Whether your goal is to write a novel or to live your life in the fullest way you can, the two are pretty much the same thing, and the end result is that you are able to lead a more creative and

full life with your mind and heart more open. That is the goal that I believe we all have.

Q. I imagine a lot of grief must have come up for you in your meditation as you watched your mother's personality fade away from you. Was that part of your meditation?

A. That was interesting. When my dad was dying, I wasn't ready for it; not that we ever really are, but I really wasn't ready for what happened when my dad started to actively die. I was really angry. I realized for the first time that there was absolutely nothing I could do about this. I was completely impotent in the face of his illness and his dying. I couldn't help him. I couldn't make it better. I couldn't cure him. I couldn't do his suffering for him. I would have given anything to have stepped in and taken on some of that, but I couldn't. There was nothing I could do except to show up and be with him. Watching someone you love die really teaches us how little control we have over many things in our life.

You truly have to be open and receptive to whatever arises in the moment. With my dad it was a lot of painful stuff, a lot of anger and grief that was probably not necessary in the sense that it didn't really help him and it just tortured me. On the other hand it was necessary. It was precisely that anger and that grief that gave me a very strong motivation to find a meditation practice and to get ready to do what I could do, to prepare as best I could, for the loss of my mom.

Life is a terminal condition. Baba Ram Dass used to say, "I am suffering from a sexually transmitted terminal condition called life," and it's true. I knew I was in it for the long haul with my mom, and eventually for myself and everyone I know and love, as well. So, to answer your question, with my mom, it was hard and painful to watch, but because of the meditation practice, I was a bit more prepared. Alzheimer's is a very slow, protracted kind of losing. You lose a little bit every day. Suddenly my mom would come back a little bit, and I would feel excited, saying to myself, "Oh, oh, she is back!" Then, of course, whoever it was that I was identifying as Mom and as "coming back" would change again.



Q. How did you handle that emotionally? Your Mom is “back” and then she is gone again. How did you think about that in terms of your meditation and coping?

A. It was very much a process of just taking it for what it was, staying in the moment. “Oh, here is this person that I recognize as my mom who is here now.” This feels good. This feels wonderful. Then when that situation would change and the person who I recognized as my mom would go away again, I would try to remember that, well, the person who is here now feels like a different person but in fact it is also Mom. All of these presentations are Mom.

I was very lucky because Alzheimer’s can be so challenging, and there are so many different ways the illness presents itself. My Mom was never terribly agitated. She was never terribly angry. On the whole, it was a quieter transition for her than it is for many others, and I think that made it easier for me. I did not have to watch her suffer and be terribly agitated or upset or confused. She was very philosophical about this.

I asked her once, “Mom, are you worried about this? Are you upset about this, about losing your memory?” She thought about it, shook

her head and said, "If worrying about it would help, I would really worry about it a lot. But, I know that worrying about it is not going to help. So I try not to. It is not going to help."

I tried to learn from her, to take that to heart and realize that no matter what happens here, it is not going to be helped by worrying about it, being upset about it. The best thing I can do for her and for myself and for everyone else around me is to just really try to accept whatever it is that comes up and to somehow be okay with it. She modeled that so beautifully. In that sense it was much easier for me with her. This is not to say that grief does not come up. Of course it does. There still is a lot of sadness around losing someone who is so dear to you. Still, my Mom was really amazing to teach me these very important lessons.

When her reality started to shift to the point where she could not remember or distinguish day from night, or Monday from Saturday, you start to realize that it really doesn't matter. These things are constructs. If she thinks she is forty years old in Hilo Hawaii, great! What is wrong with that? If she thinks Dad is still alive, what is wrong with that? That is fine.

I stopped trying to insist on my version of reality and was just trying to go with hers. It really didn't matter, because who's to say that my version of reality is so great? How do I know that is real? It just happens to be what I believe at this moment and I am sure that will change again and again. You know everything is going to change.

What I think is that my reality right now is certainly going to change. No question about it. Why should I get so fixed on it? My mom has a version of reality that works for her. That's fine with me.

Then it became a question of just being curious about it. That was huge, too. Not just to be open to her differing sense of what is going on, but to be curious about it and to ask questions, to try and understand where she is as much as possible.

It becomes something you can talk about. One of the things I found so difficult was finding things to talk about with somebody whose experience of the moment is so fundamentally different from yours and is changing so erratically. But if you cultivate curiosity, then there is much to talk about and to ask about.

It is fine to say, "Yes. I can be with somebody who is suffering or disabled." What is important is to show up. What is important is to

just be with that someone. That is fine, but what do you do when you are actually sitting with that someone and it hurts? How do you cope with what feels like such a huge loss? How do you make the connection with that person? With Mom I just tried to be curious, ask her questions so that I would know more, and so she could have the fun of telling me and explaining things. She was just such an amazing teacher.

I want to talk about this idea of caretaking. We assign ourselves roles in life. My role is the caretaker. My mother's role is the Alzheimer's patient. Therefore, I have these pre-assigned things I need to do, and she has these pre-assigned things that she needs to do. But of course, that's not quite the case. It's a much more fluid situation, especially because she is my mother.

I remember there was this time when I had to leave for some book events, and I knew I was going to be away for a couple of weeks. I didn't know how her illness was going to progress. I realized when I got back she might not remember who I was, or something else might have happened and she might not be here at all. Leaving was very painful and emotional for me. I was anticipating all sorts of things that could happen during that time when I was gone and was worrying about them and fretting and making myself quite upset.

So the time came to leave and I went into say goodbye to her. At that point she wasn't using much language. She wasn't really able to talk that much. It was stressful for her and tiring for her to talk. We were lying in her bed together, and the enormity of it just hit me, and I started to cry. This was something I really didn't want to do. I really, really didn't want to cry because I didn't want to upset her. I felt that showing my grief would upset and confuse her. After all, I was the caretaker. My job was to console her, not to confuse or upset her. But I couldn't help it. I started to cry, and I couldn't stop or do anything about it. I lay there crying, and she noticed, and she put her arms around me and started to console me. It was amazing, but why should it be? She is my mother. That's her job, to console me.

Somebody else, a very wise health aide, who was not a meditator and not a Zen practitioner, had to point this out to me later when I was castigating myself for not being stronger. She said, "Ruth. She is your mom. That's her role and she's really good at it. Isn't it great that you were able to give her something to do that she is really good at? There's not much that she is good at now, but she could give you that."

This was incredibly profound to me. Oh my God! Here I have been trying to be the super caretaker when in fact the best thing I can do is just be really honest about what I am feeling, especially when it comes to something as basic as feeling love and grief for my mother. Why not just show that?

Q. You mention worrying and fretting, and how miserable you can make yourself. There is so little that we can really control, especially in terms of living and dying. At some point during your trip, were you able to work through the worrying and fretting and get back to the place of acceptance? That this is simply what it is that happened when your mom comforted you?

A. I think that is exactly what happened when my mom comforted me. As I was lying there—I felt so tiny then—she had her arms around me—she was patting me on the head—and I felt like a little kid again.

It was this amazing feeling of realizing she was okay. It was going back to the same way as when you are a little kid and your mom can make it all better, a returning to a sense of trust, that whatever happens, whatever comes up in the moment, that it is okay. This is not to say that I didn't go back to worrying and fretting. To some extent we are hard-wired for that, and it's not a bad thing. It does keep us alert. It keeps us on our toes. To some extent worrying is probably a good survival skill. But you can do it too much, and distress starts to take over.

What I'm slowly learning from years of meditation and daily practice is to recognize when the worries get obsessive. My pattern recognition skills are improving, and I can more easily see when something becomes a habitual pattern that is not useful to me anymore. If we can just be ourselves when we practice on the cushion, we can begin to recognize these reoccurring thoughts and habits of mind. Once recognized, we can release them. We let them go. We realize that they are just old habits of mind, stories we tell ourselves, and not the reality of our life.

That is something I feel more and more the longer I practice—this ability to distinguish between what is, in the present moment, and what are the residues of thoughts and worries and habits from the past.

Q. What do you do specifically when you meditate? There are many forms and practices people refer to as meditation. How do you practice?

- A. I follow a Soto Zen practice, called shikantaza, or “just sitting,” which is very simple. The first thing to understand is that even though we think of meditation as something that happens in our mind, it’s really something that we do with our body. So the first thing I do is to pay attention to my body and my posture.

Sometimes I sit on the floor, cross-legged in half lotus, with one foot on my thigh and the other foot tucked underneath.

Sometimes I sit in a Burmese posture, legs crossed but my feet are in front of me, resting on the floor.

Sometimes I kneel using a kneeling bench.

Sometimes I sit in a chair.

The position I take depends on how my body feels at the time. I do have lower back disc problems and arthritis in my knee. Sometimes I can’t sit on the floor with a cushion as it hurts too much. At those times a chair is exactly what I need.

When I sit down, I try and feel my body in my seated position. I lengthen my spine, but not rigidly, trying to feel a sense of lifting from the top of my head, keeping my back straight but with a gentle arch in the lower part. I balance on my sit bones with my knees grounded on the floor, or my feet grounded (if I am sitting in a chair). I put my hands in what’s called the “cosmic mudra,” placing my left hand on my right palm, and allowing my thumb tips to touch so that my hands form a little oval, which I rest on my lap. You can also rest your hands on your knees or on your thighs. That works just fine, too. Then, sitting in this gentle, relaxed but upright posture, I start to pay attention to my breathing. I pay attention to my breath coming in and then going out, letting my mind simply be aware of my breathing. I do not breathe in any particular way. I just focus awareness gently on my usual way of breathing.

Very often I will start by counting my breaths. I have a fairly agitated mind much of the time, which is something I probably have in common with many other people. Sometimes counting my breaths helps. I count my exhalations. I exhale and count “one”—just counting quietly to myself. I am not making any kind of noise when I do

it, or saying the words out loud. I just very gently—when I exhale—think “one.” Then inhale and exhale and think “two.” I count up to ten. Then, when I reach ten—if I reach ten—I will start again at one.

Very likely I won’t reach ten. Very likely I may not even reach three, when suddenly I realize I am worrying about something else and forgotten to count. I realize I am not actually here in my body at all, and it’s already tomorrow in my mind, and I am worrying about something I need to be doing. At that point, without judging, I just notice what has happened and gently start again, counting at one. Eventually I may make it to ten, but it doesn’t matter if I don’t. Really, counting breaths is about giving yourself something to come back to when you notice that your mind has strayed away from the present moment.

Our minds are built to think. They are built to worry about us, to work for us, to keep us safe by thinking ahead and watching out for danger. It is perfectly normal, so counting the breaths is a helpful ground to come back to, without being judgmental, because this is a useful thing that our mind is doing for us. My attitude toward my mind is just, “Thank you for worrying about me, but you don’t need to do that now.”

Q. You don’t criticize those thoughts? You just acknowledge them, and return to your breath knowing that the thoughts will continue to come?

A. Maybe they just need to come to say hello every day, or every minute. That’s fine. The problem is when you think, “I am going to sit down and meditate. I am not supposed to have any thoughts now.” Taking that attitude, you start to feel that thinking thoughts is wrong, that they are bad. Actually, they are normal. In fact, once again, it’s just your mind trying to help you, trying to do what it is made to do. So I try to cultivate a sense of gratitude toward these thoughts, which are just thoughts after all. Rather than a sense of condemnation, have a sense of gratitude and gratefully let the thoughts go. Then start again.

Sometimes—I noticed this when I was in the throes of grieving for my dad—a lot of strong emotion comes up for me. My response to that was not to become agitated but to become incredibly sleepy. I felt like my mind and my heart were shutting down. The easiest thing to do was just to sleep. The minute I would sit down on the cushion I would

start to drift off. At that time, counting my breath was the surest way of putting me to sleep. Counting the breath in that case was probably not the right thing for me to do. It was not a technique that worked for me because it was too monotonous and easily encouraged avoidance of the present moment. At that time I tried experiencing the breath as energizing, feeling the breath as a kind of a brightening.

I attended to the breath going through my body in a very energizing and brightening sort of way, without actually counting. That way I was able to stay present in my body and mind. You can work with the practice of meditation differently depending on what your emotional state is. That is OK.

And if you're doing the breath counting—after you do it for a while you may feel like your mind is steady enough at that point to stop counting. At that point you are just sitting, being aware of your breathing, being aware of the world around you, being aware of everything in this very open state of being.

That is the trajectory of my meditations. I will start with being aware of the body, then bring my awareness to my breath, count my breathing, and then let go of even that focus of awareness and just sit. This is why in Zen we call our practice just sitting. That is really what you are doing—just sitting. So from the outside it looks as if you are doing nothing, but there is an intense internal process happening.

Q. Your mother was Japanese. Did she have any kind of Buddhist or Zen practice at all in her life?

A. She didn't. She was raised by two practicing Zen Buddhists. Both of my grandparents practiced meditation. In fact my first memory as a very young child was around the time I was three. My grandparents had come to visit us in Connecticut. It was morning. My mom sent me in to call them for breakfast. They were staying in my parents' bedroom. I went into the bedroom and saw them sitting on the floor on either side of the bed cross-legged, rocking gently back and forth. It totally freaked me out.

Grownups were not supposed to sit on the floor in Connecticut during the 1950s. I was three and very little, and here were these adults, who were eye level with me, sitting on the floor, rocking. Very often at the end of meditation we will rock gently back and forth to bring movement back into our bodies. That is what they were doing.

Of course, I had no idea at the time. I went running back into the kitchen to tell my mother and I think she tried to explain it to me. Although my mom didn't have any kind of meditation practice and was not a practicing Buddhist herself, she was raised with a certain kind of ambient background level of Buddhist practice and philosophy. I felt it really came out in the end of her life where she was able to move into her Alzheimer's illness and be with it in a very relaxed and philosophical way.

At the very end of her life when she was eighty-eight years old, she developed cancer of the jaw in addition to the Alzheimer's. This was when things really got hard. She couldn't remember from day to day what was wrong with her. She had this big hole in her jaw, this tumor. It was bone cancer that created a huge abscess on her jaw that was very painful and messy. It was on her face. She couldn't remember what it was and what was happening to her. She wasn't really speaking that much, but she still was able to hold onto a patience and equanimity that was astonishing.

By then she was in a nursing home because she needed around-the-clock care. We moved her down to the city, and I moved down with her so I could be with her.

We did palliative radiation. That helped for a while. Radiation on your face requires a lot of very uncomfortable procedures. She was able to bear the process without causing a lot of additional suffering for herself or for other people around her.

Certainly when I was a child I do not remember her as being a particularly patient person. In fact, I remember her as being quite impatient. So it was remarkable to see how she was able to change; it was a great lesson for me.

I learned so much from my parents at the end of their lives. I experienced a great shift in understanding, watching the process of my father's illness and death, and seeing the amount of remorse that he suffered at the end of his life. He suffered tremendous remorse for all of the things he hadn't been able to take care of, all of the ways he thought he failed. It was extremely painful, because I'm like him.

My dad was a perfectionist, and I inherited that from him. I also have his capacity for remorse and self-flagellation to some extent. I did not want to end up on my death bed castigating myself the way he did. The things he blamed himself for were just not true or important.

There was nothing he could do about it, yet he was still suffering so terribly.

That was a huge incentive for me to start to meditate and to learn to be okay of that with the way things are and—as much as possible—to learn to let go of remorse. Meditation has really helped that. It is not that I don't regret things that I have done. I still have a tremendous capacity for regret. I also understand the way that you can become very attached to the stories of the past. It is not going to help your present condition and it is certainly not going to help anybody in the future.

Now I have developed at least a little capacity to differentiate and to just let things go—to not cause more suffering than is necessary in any given moment. That is something that I learned from my father. I am so grateful to him. I wish that he did not have to suffer like he did, but I am so grateful to him for sharing his suffering. It certainly helped me tremendously. I hope that it helped my mom, too. I was much more able to be fully with her during the last six years of her life.

Q. As an author, you travel on book tours. You are a very committed writer. You have a partner. You have a steady meditation practice. To truly BE there for your mom in that consistent way—what tremendous devotion you have to all of the endeavors you choose.

A. Maybe that's just my dad's perfectionism! But actually, I think it's that when I sit and find my center and ground, I can do quite a lot without freaking myself out. But even so, there were many times when I thought it was all too much. I can't do it all.

Q. You speak of practicing every day and that you are always practicing, but you never really finish. Is that true? You sit down and say, "I did not quite get it right yesterday, so I am going to practice again today?"

A. That is right. Exactly. Practice makes perfect, knowing full well you will never reach that perfection, because it doesn't really exist. Or, as Suzuki Roshi might say, we already are perfect, and we can all use a little improvement. I love that term, "practice." It is something you practice every day, knowing that there will never be an end to it. That is true for just about everything, isn't it?

It is true for my writing certainly. Writing is a practice. I will never get it right. I will never get it one hundred percent. If you do, you have to stop. If I ever wrote a book perfectly, I would have to stop writing because that would be that. Hopefully I never will.

Q. Ruth, what do you think are the most important things for a caregiver to know and understand about the person they are working with?

A. The most important thing for me was to realize that caretaking isn't about making things better. It isn't about fixing things, fixing the other person, fixing a situation. It is just the practice of showing up, of just being there, willing to be open to the uncertainty of the situation. I also want to say I could have never have done this without the support of my partner, Oliver. He was so good with mom and met all the different challenges great patience.

Q. Does he meditate with you?

A. Sometimes. But for him, being outside, being outdoors is his way of meditating, of reaching into his true self. He works in the field of perma-culture and so is very aware of the meaningfulness of the environment. He also has chronic fatigue syndrome so struggles with illness personally.

Regarding what to expect when care taking of a loved one, the uncertainty can feel unbearable sometimes, so we want to control it and feel certain again. We get ourselves all tied up in knots around control. We try and control a person's illness, or our own illness. We think we should be doing something about it, to fix this unbearable situation that is broken. And sometimes we can, but often, we can't. Or, we can fix it a little bit, but we can't fix it completely. We can adjust somebody's pillow, but we can't cure them of cancer.

What is truly important is just showing up and being supportive of either yourself, if it is you who is ill, or to the person who is ill, but not in an aggressive way of trying to fix it and make it all better and make it go away. That is a denial of what is actually happening. It doesn't feel right to deny what is actually happening. I couldn't fix everything. That was probably the most important lesson that learned. That, and

that it's okay if I don't fix anything. Just being there with your loved one who is suffering, and sharing that suffering, is enough.

- Q. You were actually taking care of two people in some ways, though it sounds like your husband was able to be there for his illness and also be there for your mom. What a tremendous effort you both have made to come to terms with life's limitations, as well as nurturing your own creative process. Thank you for sharing your experiences with us and sharing how meditation has helped you cope with the enormous challenges you faced with your parents. Is there a way people can find out more about you and your writings?**
- A. My website is ruthozeki.com I have a PDF copy of the article I wrote for *Shambala Sun* magazine about my Mom. That is up on the website. People may download if they like. It was a wonderful article to write.



This chapter is dedicated to the memory
of Darlene Cohen, who gave the gift of feeling well
to so many people while being ill.

Namaste.

NW: I am grieved to report that Darlene Cohen died of cancer on January 12, 2011. Her ability to cope with arthritis, practice Zen as an ordained priest and share her invaluable knowledge of practicing with pain has always been a great inspiration to me as I am sure it was to so many others. Her enthusiasm and ability to offer hope to those who suffer illness will be deeply missed.

More information can be found at: www.darlenecohen.net.



Darlene Cohen

Even Arthritics Can Dance

Darlene Cohen was ordained as a Zen priest in 1999. She was always more interested in what happens when we get up off our meditation pillows and face our everyday work and family situations than in a strictly monastic setting for practice. She spent the vast majority of her Zen training—thirty years—as a laywoman, working along with her husband to support their family.

Working as a legal secretary, she saved money to train at Tassajara Zen Mountain Center. Then, after developing the rheumatoid arthritis that had also plagued her mother, she became a body worker/movement teacher for people with joint restrictions. Longtime experience with clients in unremitting pain and her own physical difficulties allowed her to become an incredible resource for people in pain.

Darlene gave workshops at meditation centers, seminars at medical facilities, spoke at conferences, and counseled others on how to make the relationship between suffering and delight more fluid in our own bodily experience. Darlene also wrote several books on living with chronic pain.

Q. You were a healthy woman studying at the San Francisco Zen Center when you were suddenly stricken with severe rheumatoid arthritis (RA). Is my understanding correct?

- A. It began in my seventh year of Zen practice. My mom had it. The two of us are the only ones in the family. The odd thing is that when I first started sitting Zen meditation, all my joints would swell up at the very beginning. I was a young woman in my late twenties. It would just go away as soon as I stopped sitting. If I sat for five days, I would be quite swollen for five days.

The way I handled that is that I would not eat during the sitting. I ate very little, so there was very little for my body to process. That helped with the swelling tremendously. Fasting has been a very effective thing I have done for my rheumatoid arthritis. Of course, it is no way to live, so I don't do it very often. I used to do it once a week.

As the disease progressed I became an invalid for about a year. I was lucky that I lived in the San Francisco Zen Center housing because volunteers did everything for me: they cooked my meals, they cleaned my room, they washed my hair, they did my laundry, took care of my three-year-old son. I could not do anything for myself because of my pain and weakness. Even changing my posture in bed was a dramatic event. When I had to get up to go to the bathroom, it was like going on a safari. I would think, "How can I move my legs?" It might take a good fifteen minutes to prepare my body to move and go where I had to go.

I had already been practicing meditation for seven years when that happened to me. Over time, I wanted to continue my training without the use of the powerful medications in use for RA at the time—I hoped to find an alternative path that would not weaken my immune system, as most RA drugs are designed to do because RA is an autoimmune disorder. So... I began to figure out how to get better. As it turned out, my Zen meditation training was a very great help to me.

Q. One of the questions asked often by students is: How can I meditate when my body won't cooperate?

- A. You have to meditate with the body you have. Of course, you can't throw yourself into a half-lotus or sit for five hours without moving. That is ridiculous. I have developed alternative postures.

In my book *Turning Suffering Inside Out* there is a whole chapter on different meditation postures. I have taught them to people with chronic back pain and arthritis. I have even taught them to people in wheelchairs.

Vickie Austin is a wonderful yoga teacher at the San Francisco Zen Center. She used to be the president of the Zen Center. She and I developed some lying-down postures that have the same element of alertness that the full-lotus positions have. Those are in my book. People call me from all over the country commenting on those, telling me how they have adapted those postures to their body.

I have written a little booklet with a student of mine, who has very bad back pain and cannot sit for even five minutes. We will soon send it out to many of the Zen centers in the country, in the hope that people with particular physical problems will no longer think that meditation is confined to a particular posture. There are certain conditions that have to be met to make what you are practicing zazen, like a straight spine and enough alertness to be generally aware of your surroundings. Often lying on your back can be difficult as you tend to you fall asleep. We have built some things into the postures that keep you awake. It is very effective.

Q. When I first started practicing, I tried “competitive” Zen.

I knew I could not do a lotus position or even half-lotus, but I tried to sit Burmese-style and was miserable for least the first few years of practice.

A. I am astonished you tried it for a year. You must be a very dedicated reincarnation of a lama or something.

Q. Just stubborn I think. More often than not I now sit in a chair or even lay down on my cushions. My teacher told me, “Lay down,” after I went to him crying, saying “I am going crazy with pain. I’m arthritic! I can’t do this practice.” When he suggested I lay down I asked, “That is okay, in the Zendo, in front of everyone?” He said, “Of course. The idea is to focus on your breathing and lengthen the spine, not to torture yourself.” He said zazen can be done lying down, sitting in a chair, or whatever works for each individual’s body. But then,

you know that. How do you meditate with your specific pain?

- A. I never had an easy body, ever. It was always very painful, even before I had arthritis. I have always had a very stiff, tight body, with no particular diagnosis attached to it. I always did. I took dancing as a child and was just terrible! The teacher was always commenting that I couldn't do the splits or I couldn't do this and that. I just had a body that was destined to become arthritic, even though I was very athletic at the more gross motor activities—running, throwing, kicking.

I developed rheumatoid arthritis my seventh year of Zen practice and I did not sit for about five years after that. Instead I did a meditation on movement that I invented. I imagine it has been invented many, many times before me, but it is a system that I teach now to people who have trouble sitting and who probably shouldn't sit still.

You lie on your back. You do tiny little movements, very meditative movements. I do this during all the sesshins that I lead, even for people who have no physical problems with sitting. A sesshin is a retreat for several days that is pretty intense. You completely leave your regular life behind and focus on your awareness of your immediate environment, internal and external. Sesshins involve multiple periods of sitting zazen, often from five in the morning until nine or later at night. Such a schedule can be very hard on an arthritic body.

When senior teachers Blanche Hartman and Michael Wenger invited me back to Zen Center to teach I said "I can't teach zazen." I did not sit traditional zazen. They said that "this is 21st century America. You can teach anything you want." I discovered that not only could I teach zazen, but that during time I was an invalid, I seemed to have developed a very deep understanding of the physical mechanics of zazen.

If you can just sit down and flop your body into a full lotus, you do not necessarily understand zazen. I have a master's degree in neurophysiology, so I always saw the little movements I developed as neurological. In other words, the brain is teaching parts of the body how to move—which is how I recovered from being an invalid. I just gradually taught parts of my body how to do movements that they could not do before. I found out that there is a whole system of these little movements taught from the same point of view that I teach them, called

Feldenkrais movements. I was intuitively doing something similar to Feldenkrais practitioners, who are quite advanced at understanding neurological movement. The fact is that if you are a person in a great deal of pain, the first step is to relax the nervous system.

I did my little movements instead of traditional zazen for about five years. Then I was invited back to the Zen center to teach. Since I had to develop all these alternative postures, I developed a very subtle understanding of the body's participation. Currently I sit in a chair. Sitting in a chair is a difficult way to sit in meditation, but it is frequently the only way that many people can practice.

Every place you go, it is a different chair. You are always reinventing your posture, depending on the contours of the chair, use of support cushions or other means to keep your back straight, feet on the floor in the best approximation of the "three point" or triangular position, that is best for full body "openness" to full breathing.

Q. I typically use a back support cushion when I use a chair. So many Western chairs are built with the back slanting backwards, which does not encourage a straight spine. I understand that with more practice and discipline one can learn to hold their spine up. Would you recommend the use of a back support cushion?

A. Every chair is different. I get around that by sitting on the edge of the chair so my feet are solidly on the floor, which I think is absolutely essential. During a long sitting, like seven days, I will put a cushion under my feet on the floor so that I can sit back and have my back supported over a long period of zazen.

Another thing you do not want is to have your legs hanging down from the chair's seat as it will cut off the circulation. I am very short and it is a rare chair that allows my feet to touch the floor.

Q. You have developed this approach of using little movements that rejuvenate your neurological system. People with Parkinson's symptoms will be fascinated, as will arthritics like me. Where can we learn more about your techniques?

A. I refer people to Feldenkrais classes, and my book *Turning Suffering Inside Out* describes many of those movements, as does

my book, *ARTHRITIS: Everyday Exercises for Body and Mind*. In the arthritis book, there is a whole section on neurological movements. And on my website, you can order two CDs, as well as the book. One of the CDs, “Meditation on Movement,” is fifty minutes of practicing the little movements I have been speaking of.

Q. Is it rather individualistic? Does each person have to start from the basics of your philosophy and then adapt it to their own body?

A. Not really. These movements are so small that anybody can do them. They can generalize pretty easily. Some people have asked “How can I best manage my time, my marriage and family, helping with household chores, medications, meditations, and all, with so little strength? A three-year-old son is going to want me more than anybody else.”

First of all, living with other people who can help you is the most important thing. If you are debilitated and weak and in pain, you have to be happy, feel supported. Otherwise, you will have a miserable existence. Often it is difficult for other people to relate to you, since you are so slow and weak. In turn it is also difficult for you to relate to others, especially healthy people because our culture puts such an emphasis on speed and acquisition.

In my family, with my husband and my young son, it was very important that I pay attention to pleasure. I did the things that needed to be done, of course, taking a lot of attention to my own sense of care of my son and the household things very slowly and with a great deal of patience. If you read my book on movement and RA, it will help you learn how to submerge yourself completely in doing housework and dressing yourself, so that those activities are deeply satisfying. I describe washing the dishes—feeling the soapy water on my arthritic hands, folding laundry, smelling laundry. It was very important to me that I enjoy these tasks. Even if you don’t get everything done, it is more important that you do what you do with great joy. The only way you can do that is to do it with your full attention.

Q. You are talking about being very mindful in each movement?

A. I am. I always tell clients and students that when you have a chronic or a debilitating disease, there are two arenas you have to work in. One is to do all the research, see the doctors, do alternative therapies, do everything you can to stop your pain and stop the progress of your disease. The second thing to do, at the same time, is to cultivate a mind that is willing to live with your situation for the rest of your life. This requires that you practice meditation and mindfulness.

Q. Sometimes that feels like a lifelong prison sentence to people in my psychotherapy practice; it is very hard to change their minds when they feel so weak and powerless over their bodies.

A. You cannot convince anyone of anything. You can only point to something that might help them. They make their own decisions.

Would you rather live a miserable life or would you rather—with the situation you have—have the most joyful life possible? For me, I was determined to enjoy my life. That is number one for me. Of course, since I am very limited in what I can do, I make sure that as much as possible, I do what I enjoy. This is not something you know intuitively. There are skills that have to be cultivated, skills developed by meditation. These are critical to having a life that you love, even if you have chronic pain and illness.

One skill is to learn to focus at will. Whenever your mind wanders away from your breath, you gently bring it back. Over time, you can focus on what you want to focus on. Anyone who does breathing meditation—in the Zen or Vipassana tradition—knows this technique. Pain is such a compelling object of focus that if you have not cultivated this ability to focus at will, it will hijack your consciousness over and over. You won't be able to do anything besides think about your pain.

I don't know anything better than breath meditation practice for learning to focus at will. I think of it like training a puppy. You just keep putting the puppy back on the newspaper. Of course, you never hit the puppy or scold the puppy. The puppy eventually learns.

The second skill is shikantaza, the Zen meditation practice of just sitting and allowing a panoramic focus. This is actually essential to the art of living: being able to include everything, not having a preference

for one string of thought over another string of thought, but including everything that passes through your mind. I never enter a room today without looking around at the room and seeing what in this room will comfort and soothe me. I look for things such as handmade vases, a wooden floor, a quilt, a handmade throw, a comfortable chair, light coming in a certain way.

You may have to look pretty closely for comforts in a hospital room, but sometimes there is a nice view out the window. There could be pillows and specially warmed blankets. Don't compare it with other rooms, just be in the room you are in. This ability to include everything in your focus leads eventually to the refinement of consciousness. It enriches your pleasure in life exponentially.

Try noticing ten things that you are conscious of at any particular time. Let's say you are sitting on a chair and noticing the sounds in the back ground, try noticing what you see out of your eyes, and so on. You can get to ten things pretty quickly. If pain is one of those things, that is too much. That pain—one out of ten—will hijack your consciousness every time. The other nine things can't possibly offset the compelling quality of pain.

But if you begin to include in your meditations all the things that appear to you—and the quieter you are, the more things can appear—you can begin to notice close to one hundred things on a pretty consistent basis. You'll notice more subtle things, like the shadows, an animal presence, the sound of the air conditioner, the temperature differences between one side of your body and another, the brush of your clothes against your skin. If you get to one hundred things, and if pain is one of those one hundred things, that is the pain you can bear. That is what I mean about refining your consciousness.

Q. It makes so much sense not to make pain your primary focus. In support of this “cognitive shift” away from one thing to many, there is now neurological research which shows, through cutting-edge brain imaging, that as you allow other thoughts to enter your mind during pain, the actual area of the brain processing the pain becomes smaller in relation to all the other areas you are devoting to other thought processes.

(The Human Brain Book; Carter, R., Aldridge, S., Page, M., Parker, S.; ©2009 Dorling Kindersley United; London, New York, Melbourne, Munich, and Delhi)

- A. In a sense, all things are equal in Zen. Pain is pain. Sunlight is the sunlight. The shadows are the shadows. If you can give equal attention to them all, it will be amazing to let so many things come in and out of your sensory perception.

That is what I mean by enriching your life exponentially—things on the level of the satisfaction you can feel, if you allow yourself, when you consciously put a cup on a table. The flat surfaces meet. This is a rare and satisfying experience. It is the minutiae of everyday life, but now you are noticing it.

Mostly we just notice things that have to do with satisfying a particular appetite we experience in the moment—if we are hungry, we notice where the food is. If we are lonely, we notice where the people are. I am talking about noticing and observing everything at the time; being present exactly where you are.

Q. You said earlier that it is important to look at the medical aspects of your condition, make sure you understand it, and do what you can do. What are your thoughts on using medicine to help?

- A. When I got rheumatoid arthritis in the late 1970s, doctors offered me a bunch of medicines that I was not interested in. I was only thirty-five years old. I did not think I could take prednisone or some of the other medicines that affect your eyes or internal organs over time. My doctor was very honest. He said we don't have anything that won't destroy your liver and kidneys over time, so you can probably only take these medicines for ten years or so. Hopefully, by then, we will have developed something else. I thought: If in ten years I am going to have to go off these medicines, I might as well not start. I didn't start.

I never took arthritis medicine until I was sixty years old. By then, old age had really caught up with my efforts to handle this disease without medicine. What I was doing was the little neurological movements and exercises, swimming four times a week, and walking every day. I would say that my self-help program was almost like a part-time job.

I have always been in great health for that reason. The self-help program has all these wonderful side effects. I didn't have to wear glasses

any more after a while. I was hypothyroid before I developed rheumatoid arthritis. After I started doing these exercises, my thyroid became normal. Except for rheumatoid arthritis, I was great.

At age sixty, I began slowing down. I figured out I would probably have to do three or four hours of exercise a day to keep up with the disease. I went to my rheumatologist once a year to check out what was going on. He threatened many times to stop being my doctor because he was so frustrated that I wouldn't ever take medicine. But finally, at age sixty, I asked: "What do you have? I am ready for it."

He said, "Well, I have these biologics. Remicade, Enbrel."

I said, "Well, do they wreck your liver and kidneys?"

He said, "They do a lot of terrible things to very few people. You may not be one of those people."

I said, "Well, I will give it a try."

I started taking Remicade. What a miracle! I was so happy with that drug. It really made me feel like I didn't have rheumatoid arthritis. Everyone commented about how I was moving around with ease. I had always hiked. If I hiked with friends, they would hike in front of me and come back, hike ahead again and come back... you know—like a dog will run ahead of you and come back. I was so slow. I am willing to hike. I love to hike. But I am not really the best hiking companion. Still, very compassionate people would go out hiking with me.

I would also go dancing. It is probably not the most pleasant thing to watch me dance. The Remicade made such a difference that I could keep up with people on the trails. Nobody could believe it. My husband, who has walked with me down to the post office and all around the city for years, could walk at a normal pace and I kept up.

Q. That is great! Are you able to continue on that?

A. No, I had to stop when I got cancer. There are no statistics on this, of course, but I actually think since Remicade and Enbrel both suppress the part of the immune system that prevents tumors, that if Remicade did not cause my tumor, it at least enabled it. I now have chemotherapy, which suppresses the immune system. It is not as effective as Remicade, but it does keep my arthritis in check.

Q. You have such a positive attitude, given what you have had to deal with all these years— not only the arthritis, but then to be hit with the cancer as well.

A. It is really unfair. I find it quite annoying. I am not so sure there is a reason, but I have to say—of all the people that I personally know who could have had all this happen to them, I am probably the best person. I am very disciplined. I have a tremendous amount of vitality. I am probably the best adapted.

Q. Regarding a disease like Parkinson's, with the attendant suffering of stiffness and pain, how can one relieve those symptoms? What would you suggest?"

A. I think the micro-movements would be very good for Parkinson's Disease. Here is the thing that I have learned. Nobody likes to do exercises. In order to have a regular exercise time—at least four times a week—you really have to do movements that: (a) you enjoy doing while you are doing them; and (b) they make you feel better afterward. I never could have done my exercise program every day for thirty-five years if I didn't enjoy it so much and if I did not feel so much better afterward.

Rheumatoid arthritis is the worst in the morning. I just barely get to the toilet, now that I don't have Remicade to help. Then I get to my exercise room, put down my mat, lower myself onto the floor, and start doing the exercises. Within a half hour I am a different person, psychologically as well as physically. These exercises have positive side effects—because they are neurologically based. If I am in a snit about something, if I am mad at somebody or over some event, if I am inconvenienced or whatever—by the time I am finished with my exercises, I am emotionally restored.

It is that little bit of space similar to somebody sitting in a café drinking their coffee, reading the funny pages. It is that kind of space where you are just enjoying yourself. You feel no pressure. I used to answer the phone during my exercises just to see how that affected them. I don't do that anymore. It is really good to have that time to just be feeling my body, feeling it relax. I get so many phone calls that I have to limit them. I only answer my phone two hours a day. I used to coincide that with my exercise to try and save time. It doesn't work.

Q. You mentioned you have to work with the body you have. Some people with Parkinson's ask how they can meditate when they can't stop trembling.

A. Then you do trembling meditation. It is very easy. If you are going to do meditation, you have to do the meditation that you do, that comes from your own body.

Q. ...and accept that; be okay with that. Accept that this is just how I do it?

A. If you are not okay with you, you are setting up a pretty miserable situation.

Q. I love your sense that the point of life is to enjoy life, no matter what.

A. I really think that the only way you can help other people is to actually be an example of someone who lives for something else besides acquisition and speed. I don't think there's a better way to help people than to show them the sheer joy of being alive.

There are so many people who need help. Of course, I understand the pressure. I feel that pressure, too. I really feel bad when I have a huge backlog of people who have called for advice or need help with pain.

But what is very important, again, is to enjoy life so that people can actually learn from you. If you are not able to find that joy within, how can you help others find it? If it is a few people that you don't get to right away, well... you eventually get to them. Again, I try and have my state of mind be the most important thing that I am taking care of.

Q. What do you say to the person who says, "I have so much to do that I don't have enough time to meditate? There is just not enough time in my life."

A. It comes down to your values. What kind of life do you want to live? Do you want to live a life where, on your death bed, you finally say, "Whew, I got everything done." Or do you want to say, "Boy, that was a great life. I am ready to die now." I did everything I wanted to do.

NW: Thank you, Darlene, for your great perspective on living with chronic illness. I encourage readers to check into Darlene's books and tapes. I have found them very helpful in sustaining not only my Zen practice, but in so many other challenges a chronic illness presents.



John Wiley and Norman Fischer at Shuso.



John Wiley and Carolyne Milling

Zen and Caring for a Loved One

John has been a psychotherapist for more than thirty years and has practiced Zen meditation for fifteen. His teacher is Norman Fischer of the Everyday Zen Foundation in California. John and Carolyne have been married for twenty-five years. John enjoys bicycling, gardening and other outdoor activities. In May of 2010, he received Lay Entrustment to be a certified Zen teacher.

Carolyne is an artist who has rock-and-rolled with chronic fatigue for forty years and suffered long periods of daily migraines during that time. She doesn't want to miss out on much when she is in pain, so she takes just enough medications to allow for work and fun. Chronic pain is tiring and demoralizing, so she reads many of John's Buddhist books and magazines and sits meditation with him in the evening. She also seeks out uplifting Christian books. She says that John is very compassionate, loving, and understanding of how difficult ordinary life can be some days.

Carolynne says and John agrees that since beginning his practice in Zen meditation he has become much more patient and accepting of her physical limitations. Carolynne says she feels lucky to be married to such a dear, loving man and to have over 2000 years of wisdom to lean on and learn from. She describes herself as a “Bustian” or “Chriddhist” as she benefits from the teachings of both Buddhism and Christianity.

Q. John, you have practiced Zen meditation for fifteen years. Carolynne, you have suffered with fibromyalgia, as well as migraines and other physical difficulties, for forty years. Both of you mentioned that since John has been practicing meditation, there has been a shift in your relationship that affects how he responds to your needs when you are very ill and almost incapacitated. John, you have mentioned that your patience has developed since practicing Zen. Please tell us about that transformation.

Carolynne: John became more patient, more compassionate, and he slowed down a bit after he began meditating. He wasn't so quick to snap. All those things just softened. He has been a wonderful mate. I can't imagine anyone else living with me. He has been great.

John: Meditation has helped a lot, not just with our relationship, not just with illness issues, but in my total life, in so many areas. There is a space now between something happening and my reaction to it. In that space I can think a little bit about how do I want to handle this? What is the best way to handle it? That is really helpful. Over the years I think I have noticed things I do or used to do that aren't helpful at all. I try not to do those things as much anymore. I can certainly get tightly wound up and impatient and upset when things are happening that I do want to have happen, or NOT happening when I want them to.

Over the years, I have become more able to notice what is going on and ask: “OK, how do I want to handle this?”

That really makes a difference. Meditation helps me with the practice of Buddhism. It is not just meditation. It is also practicing the precepts—generosity, patience, and ethical conduct—those concepts so integral to Zen practice. In regular meditation, I can keep those things in mind more. It also helps with accepting a situation that I

don't like. It doesn't do any good to add the thoughts: "I don't like this. I hate this. This shouldn't be happening." That just makes the situation worse. A better way to handle it is to say, "OK. This is the way it is. What is the best way for me to respond to this?"

Carolyne: I have benefited from the literature and from John talking about Buddhism. I, too, have time to think before I react to situations that I would have never chosen. I recently had to have surgery on my ankle. Pins were put on both sides. It was a big deal. I was an invalid at home for quite a while. Buddhism helped me choose to be pleasant and faithful to how I want to be. I WAS those things. I just did not want to make the situation worse. Buddhism gave me a place to go with it, a place to rest with it and be at peace. Being off my feet for so long, not being able to go out, that was what I had to practice with. My focus was to get through every day, have some fun and not freak out.

Q. It sounds as if you are not dwelling on the fact you are very physically limited right now because of your broken ankle. Instead you are saying, "Okay. What can I do despite this? What kind of different acceptance can I practice?"

Carolyne: Precisely. I appreciate every new skill I have, like when I regain my strength and am able to do the old familiar things. I love gardening. I love being out in the sun and walking more. It is wonderful. I remember when I was able to drive for the first time after my right foot was injured, I was so happy. I felt so strong.

Q. Do you have a daily meditation practice or is what you learn more from reading and learning through what John brings home?

Carolyne: John meditates a whole lot more than I do. He goes to Wednesday-night meditation. He goes to sesshins. I don't do that. He and I do sit together for about thirty minutes every day or so. That is an enjoyable thing. It is hard to do, but it is beneficial. I do get benefits from the culture when it comes to reading. I feel like my life has been so enriched by these teachings.

I am Christian. I am also Buddhist. I feel so grateful to Buddhism for helping me keep my wits about me in some conditions and situations that I would not have chosen.

Q. John, could you speak about what it has been like to be the healthier person in the relationship? How do you handle it when Caroline says: “No—I can’t do that today, I don’t have the energy”?

John: Early in our relationship, I would try to make suggestions: “Why don’t you do this? If you do this, this, and this, maybe the problem will go away, then we can do this or that thing.” I realized after too long that it was not helpful at all to make such suggestions.

No, if we have a plan to go to the farmers’ market on Saturday and if Carolyne can’t do it, I will go by myself. Or I will do something else that I want to do. Sometimes I will stay home because she is home. I am careful about that. But I am not going to deny myself too many things I enjoy because Carolyne cannot do them.

Q. There is no resentment? It is not unfair? Do you ever think she should try harder to come with you?

John: Years ago—yes. I would think: “Well, there must be something you could do to make this better. Because it is not better, you are not doing what you should be doing.” That is how I used to think. Now when there are problems, I do not blame Carolyne. I just don’t like the situation. That is different than blaming the person.

Meditation has helped me stay grateful for a lot of things in my life, to be aware of how much I have in my life that is going well. I am healthy. We have a wonderful house. Our marriage is wonderful. My daughter is doing well. I love where I live. I like my job. I have a lot of activities I enjoy. To be aware of all these things is helpful. It helps to meditate in the midst of a difficult situation.

Meditation has helped me be aware of the beauty in the world that is there all the time, no matter what is happening to me. My life could be going up in flames, but the clouds are still beautiful. The air smells good. I like the sound of the birds. I will see a parent being kind to a

child—such things are going on all the time. Just to be able to see that, even if your own life is difficult, is helpful. Meditation has helped me pay attention to those things, to not just be absorbed in my individual situation.

My Sangha had a practice period from January to March. I had these great plans about what I was going to do. I was going to teach a class. I was going to go to a couple of different meditation activities. I have a hard time when I make plans and then they must change. But with Carlyne's broken ankle, I had to change my plans, cancel the class, cut some of the meditation retreats—either attend them for a shorter time or not go at all. For a while I fought that. I kept thinking, "I don't want to do this. There must be some way I could do it anyway."

Then I realized that I needed to change the *WAY* I practiced during that period. I needed to handle this situation at home the best I could. That was my practice for those six or eight weeks: embracing the difference rather than fighting it. Meditation helps very much with that. It helps me see that fighting a situation, trying to change what cannot be changed, is a waste of energy that just makes things worse. Embracing reality as it is gives me some opportunities that I would not have had otherwise.

Carlyne: It is almost as if we were doing a dance. My role was to take the help, be grateful for the help, honor him, and try to be in each moment, enjoying reading, doing crossword puzzles, or talking to friends on the phone. It was such a harmonious thing. We talked about the possibility that this situation could provoke either one of us to verbally lacerate the other and get into this hideous merry-go-round where nobody is happy—he's mad at me; I'm mad about the pain. He could be put out about how much he was doing—taking care of me, all the wash, all the household chores.

We talked about it and decided that we didn't want to make the situation any worse than it already was. We wanted to let the other one know when we had had it and were impatient and stressed out.

John: Carlyne did an amazing job of handling the difficulties—she spent six weeks where she couldn't drive and could not put any weight on her leg. She had crutches of course, but basically she spent six weeks on the couch. I would have had such a hard time doing that. My role was easier, even though I had a lot more to do. We share all

the work during normal times—the shopping, cooking, cleaning, errands, and all of that. I had to do it all for a while.

I thought that I would rather be in my position than hers. I was so impressed that she could stay cheerful and content and read and sit there every day—all day long. She could not go upstairs to our bedroom, so she had to stay in another room. I was able to just say:

“Wow! She has a much more difficult situation to cope with than I have.” I really appreciated the job she was doing with it.

Carolyne: I was deeply touched when some friends were over and John just said, “I am not doing those dishes right now. Carolyne is my practice.” It felt like a holy experience, going beyond simply a choice not to do dishes. It was transformative.

Q. John, could you talk about what it means when you say “Carolyne is my practice”?

John: The word practice can mean a lot of things. It can mean meditation. It can mean reading. It can mean going to retreats that last anywhere from half a day to several days. Practice is life. Saying that her illness was my practice means that she was going to be my priority for a period of time. I had to pay attention to her illness and how I responded to it. I wanted to do the best I could, try to notice when I was not doing well at it, and try to take care of myself while this was going on. If somebody dies, your practice could be grief. If you lose your job, your practice could be dealing with how difficult that is and is being the best caregiver you can be.

Q. You both sound as if you have found a kind of equanimity in accepting things just as they are. Is that a fair statement?

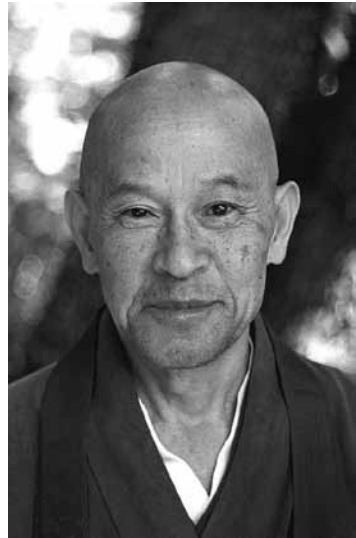
John: Over the years I have collected a few little Zen quotes that capture the essence of Zen Buddhism. Two of them that come to mind are from Suzuki Roshi:

Accept what is as it is and help it to become its best.

Make your best effort at each moment forever.

Q. Can you tell us a bit about Suzuki Roshi?

John: He lived from 1905 until 1971. He was a Japanese priest. He came over to San Francisco in the late 1950s. He founded the San Francisco Zen Center, which has three monasteries in the Bay area that are very active in teaching, training those who want to be priests, offering the Dharma, or Buddha's teachings to whoever wishes to learn. Suzuki Roshi (at right) started these centers during a time in which his superiors in Japan did not think Westerners could possibly understand, much less practice Zen Buddhism.



Suzuki Roshi wrote the book, *Zen Mind, Beginner's Mind*, which is a well-known book in Buddhist literature. Our Buddhist practice in Bellingham is based on the practice he founded in San Francisco. Our teacher, Norman Fischer, trained there in that style of practice. He comes to Bellingham several times a year to teach.

Q. What books would you recommend for someone who wants to know more about Zen?

John: I might recommend Robert Aiken's *Taking the Path of Zen*. It is a bit more accessible to people who haven't had any experience with meditation or Buddhism. Pema Chodron's book *When Things Fall Apart* is a good one as well.

Carolyne: Over time and with John's Zen practice there has been a greater degree of acceptance of difficulties. So much of Buddhism is just that. One of my favorite people is John Tarrant, who wrote *Bring Me the Rhinoceros*. He deals with many different issues regarding difficult times and how one can choose to respond to them. Sometimes I get into a twit when everything hurts and it is raining outside. I feel crummy. It is easy to globalize those feelings and feel like it is never going to go away, to think "It is always going to be like this. Nobody

likes me. I am a pain in the... whatever,” and on and on—a negative twisting in my thoughts that seems to control me.

Reading the books about Buddhism by Pema Chodron and John Tarrant reminds me that those feelings and that exasperation are like a cloud. It will move across the sky and then it is gone. Something else will take its place. Nothing lasts forever. It will pass. It is hard to take the long view sometimes when we are in the thick of it. Buddhism helps to address that. It is not forever. Nothing is forever. It is just for a while.

John: Acceptance of something isn't passive. It doesn't mean hopeless resignation or that there is nothing one can do. Carlyne is doing a lot of things to recover her health. When I accept her situation, I am doing something to help her recover her health. What acceptance means is that you do not add to the difficulties by focusing on feelings of hatred for the situation or frustration at your own helplessness.

Q. I find acceptance to be very difficult to practice in times of fear or frustration—those times when things just don't seem fair or just. How do you work with these things?

John: I find the five remembrances tremendously comforting. These sayings are from the time of the Buddha. He asked the monks and nuns who were his students to always think of these:

1. I am of the nature to grow old. There is no way to escape growing old.
2. I am of the nature to have ill health. There is no way to escape having ill health.
3. I am of the nature to die. There is no way to escape death.
4. All that is dear to me and everyone whom I love is of the nature to change. There is no way to escape being parted from them.
5. My deeds are my closest companions. I am the beneficiary of my deeds. My deeds are the ground upon which I stand. We should reflect on this.

We are all going to get sick and die and lose everything. Our children will move away. Our houses will be lived in by somebody else. My deeds are my closest companions. What that means to me is that how I act, how I behave when these challenges come up is what matters,

what will make a difference in how much I and others around me will suffer.

Q. The nature of suffering can be different depending on how one looks at it?

John: Yes, the important question is how will I respond to this situation? It is so helpful to have a path when things really get difficult.

Q. Please say more about “My deeds are what I stand on.”

John: To me, it means how you act in a situation makes a really big difference. If you act with compassion and some forethought, probably things are going to turn out better than if you just react without thought.

Carolyn: Being on the road driving is an example. A lot of times when we are driving we either act out or see others acting out very primitive behaviors. Rages. Somebody turns in front of us or forgets to signal. We see a lot of very childlike behavior in cars and that can be scary.

John: Suppose somebody does something in traffic that makes you angry. Do you want to lay on the horn and drive by and scream at them and make them become angrily aware of you? Will you act in a way that makes the situation worse by tailgating them? Or do want to take a few breaths and slow down a little bit and let them get far ahead? You can act in a way that helps the situation settle down.

Q. When you react with anger, honking and yelling, are you somehow binding that negativity to yourself?

John: It is like adding fuel to a fire.

Q. If you just take a few deep breaths and let that person go, then that situation is over.

John: Do you want to carry it around in your head, be angry? “Oh I wish I did this. Boy, I am going to do that.” That is what I am talking about.

Q. I know I have had that experience while driving, and have seen the same in my parents who taught me to drive. It's as if the rolled-up window allows you to be a beast.

Carolyne: That makes me think about how kids are imprinting on movies. There is so much very bad behavior. There is so much explosive anger, macho posturing—how do kids learn bad examples?

Q. Do you think it is about control? If the directives of our culture tell us we must be in control, how frightened and impotent we must feel in the real world where there is so little we can control.

Carolyne: Yes, as if we can have it all our way. As if, we can have control over our lives in a perfect world, where everything happens just the way we want it. That is not reality.

John: To get back to “My deeds are my closest companions.” When my father was dying, he couldn’t eat. He couldn’t talk. He was in diapers. For a couple of years before his death, he kept losing his functioning. His memory was pretty well gone. He stayed cheerful the whole time, although I don’t know how. To be with him was always a joy. He still had a sense of humor even on the last day of his life.

That was just remarkable. What an example of someone handling old age, illness, death, and losing everything so beautifully. You would think someone in that situation would be complaining and afraid and sad. I don’t know how he did it, but it was remarkable to see.

Q. Would you say he had any kind of formal mindfulness training or was this just his natural way?

John: He had his early Catholicism beaten out of him as a young man. He went to Catholic schools. He ended up not being a Catholic after that. He said he was probably one of the few people to ever tell a priest to go to hell. He had no spiritual practice. In fact, he used to say he wished he did. “I think that would be an advantage,” he would say. He was one of the kindest people I ever knew. He treated everybody really well, just naturally. He never got angry in traffic. I never heard him say a mean thing about another person, like call anybody a name

even when he was driving. I just can't believe it. I don't know how he did it.

Q. It sounds as if he did have his own spiritual practice. He just did not give it a name or a dogma.

John: He had great equanimity.

Q. That is how your dad chose to live—that balance, that acceptance, that cheerfulness. What a lovely way to live.

John: Yes, something for which one can strive to attain.

Q. I know you have mentioned in some of your talks you were not feeling much peace or equanimity in your youth. Did your father's sense of peace with the world lead you to seek a spiritual path?

John: I did not do that until much later. Now I think about him a lot. How he handled things. How he treated people. If I can do as well as he did, that would be great.

Q. You both have had incredible losses in the past few years. Carolyne, you have lost your family—your brother and your parents. John, you lost your father. How did you find the strength to cope with such rapid and profound loss?

Carolyne: When I was in the thick of grief, I heard a talk by Norman Fischer. Whatever the scenery inside my head was, it ripped open and there was all this beautiful light and color. It just burst out of this place I had been in for years. It was so wonderful.

There's a story in *Buddha Dharma*, a magazine we get, about a woman who had just been told by a friend of hers that the friend was going to die of cancer. In the process of explaining her symptoms, the friend said, "Oh my goodness. There is a flock of geese walking across the street. It is so gorgeous." She was going on and on about how darling the little goslings were. How beautiful the mama was. What a perfect day this was. She just went off like that. The woman was so impressed with her friend's ability to be able to let joy and awe into her day, even while she was busy dying.

I find that Buddhism, the writings or talks, are transformative. It doesn't erase what is going on in your life. It gives you a break, a way to take in what is happening now. This is quite beautiful. Enjoy it. I like that space. John had been practicing Buddhism for about five years when I lost my father and brother within only three months of each other. I was very close to my brother. I wish I had been more familiar with Buddhism. It was awful losing him. I think I could have given myself some breaks and said—you can be grieving, but look at the day. Look at the blossoms on the tree. I couldn't enjoy them, staying stuck in my grief.

Q. You don't feel this makes light of or minimizes your loss?

John: One of the great advantages of regular meditation is to be able to see that beauty all the time. It also helps mediate the big problems in the world you read about—genocide, environmental degradation, and political upheaval.

Such issues can really get a person downhearted. When you balance that with some of the beauty that we all have access to all the time, it helps, even though it does not change the big difficulties in the world. Meditation helps me feel everything more deeply, including pain and grief, but it also helps me let the painful feelings pass away.

Carolyne: You don't need to wear the world's problems like a huge capitalized headline. We can do what we can. That is comforting.

Q. I recall a time recently when I came to see you, Carolyne. John helped set up your easel so you could sit and paint in the living room. There you were painting this beautiful, colorful, gorgeous painting, even though your leg was in a cast and you couldn't get around. You were still expressing your art. I was so moved that you could do that, even in the midst of your pain and your imprisonment. I think that is the art of Zen. You just work with what you have. You make it work for you.

Carolyne: There really aren't a whole lot of instruction manuals when we are born for our parents to know how to parent us. I feel like Buddhism has really been the closest to giving me a clue about how to cope and experience life gracefully; to accept all kinds of situations and just be with them.

John: In my opinion, it is the regular meditation that helps me catch myself when I get off track. If I was not doing regular meditation, it would be much harder to notice things and appreciate things and see if I have said something hurtful and change my response the next time. Regular meditation is so important. Plus, it feels good to slow down and just be quiet.

Q. Could you describe what regular meditation means to you. What is it? What do you do?

John: I have a little room in the house. I sit on a cushion. I light a candle and incense. Then, once I get into the posture that I sit in—you can use a chair or a cushion or whatever—it is just a matter of checking in with my physical body, being aware of my breath, then just observing.

I notice if a thought comes up or an emotion comes up. I try to just watch it. Acknowledge it. Experience it. Then I let it pass and change into something else. If I get caught—if I am making a grocery list, for example—I say, “Okay. I am making a grocery list. Come back to my breath.” Or if I am planning what I am going to do today, I acknowledge the thought and come back to my breath. If you do that, thoughts eventually tend to quiet and settle and you can have a peaceful experience, always coming back to the breath if you get caught up by a thought or feeling. I do this for about a half hour. Some days my mind is running all over the place. I am making grocery lists, planning my day, thinking about what happened yesterday or what might happen tomorrow. Other days it is pretty peaceful.

Q. So no matter how long one has been practicing, those thoughts still intrude, still try to hook you?

John: Yes. The big advantage is when you are done meditating and are living your life, what develops over the years is a much better awareness of how your body feels, what your mind is doing, what you are feeling. Do I want to go there or not? That is extremely helpful in day-to-day life. Meditation isn't just about sitting on a cushion for a little while and then going about your life as if it didn't make a difference. Meditation really helps you be attentive and observe yourself over the course of every day.

Q. It gives you many more choices, a spaciousness to consider what you really want to do instead of just reacting?

John: Yes. In traffic, I would like to swear at the person who just cut me off, but I am not going to do that. I am going to let it go and calm myself down, and not make the situation worse. Instead perhaps I will notice what a beautiful sunset there is. Glad I noticed it.

Carolyne: I was just thinking about beauty. Looking for it gives you an enjoyable place to be in the midst of whatever you are going through. It is all around. At the moment we have chickens and a cat. The moments with those animals are timeless and joyous. Just seeing our cat playing by herself and enjoying herself is such a lot of fun. You step off the back porch, sit down, and feed the squirrels, feed the cats, feed the chickens—it is not exactly “Wild Kingdom,” but I sure get a kick out of it. Working in the garden—oh my goodness!

Q. Your health allows you to get in there and dig?

Carolyne: Yes, when I can. Creating beauty is wonderful.

Q. There is a huge connection between fear and the symptoms of illness—all kinds of chronic illness. When fear is up, the symptoms flare. When it is not up, symptoms are much better. What do you think are the mechanics for getting out of fear when you use meditation?

John: In mediation, you can't stop a thought or a feeling from happening. If you acknowledge it, experience it, and just let it pass, it will change into something else. First of all, notice the fear as early as possible. Where is it in my body? What else goes with it, what thoughts, what emotions, what memories? Acknowledge it. Let it be, without adding to it: “Oh my God. This is awful. What is going to happen? Is it going to get worse?” When you do that, you start a process that makes the fear bigger and bigger. There is a different way to deal with it through meditation. Why add fuel to the fire, so that the fear gets bigger because of how you reacted to it.

**Q. What would you like to say to anyone with a chronic disease
Carolyn?**

Carolyn: That the disease is not all there is to a person. There is so much more. Make an effort to get exercise. Make an effort to move. Do loving things. Give to other people. That is so beautiful. It is the touchstone to so many philosophies and religions.

John: Carolyn is one of the most generous people I have ever met. I have to work at it, but she has it naturally.

Carolyn: Invite someone to dinner. Go to a movie with them. My friends were so wonderful when I was hung up in the house. When they would visit, or take me out for coffee, I felt treasured, very cared for.

**Q. John, what would you say to anyone who is in a position of
caring for a loved who is chronically ill?**

John: Be kind to the person you are taking care of and to yourself. Slow your life down as much as you can so that you have a little more space to do the extra work of caretaking. That might mean letting go of some things. You can't do everything. Make sure that you take good enough care of yourself that you can keep helping the person you are caretaking.

If there are problems, don't take it out on each other, on yourself, or on the other person. Get support from other people. Our friends would bring food by once in a while or come by and visit. That was really wonderful. It is very hard to be a caretaker if you are alone.

NW: Thank you so much for sharing your wisdom. I am sure you have given hope and new ideas to many couples who live as you do. Living with a very healthy husband myself, I know how much inner conflict could arise as I cannot do the physical activities he does.

Compassion, patience and a peaceful acceptance of reality just as it is goes a long way in making a relationship joyful. Thank you for allowing us into your relationship and showing us how all this is so true.

The following is an example of Carolyne's painting.



Desert Sky



Marsha Linehan, PhD

Zen and Psychotherapy

Marsha Linehan is a Professor of Psychology and an Adjunct Professor of Psychiatry and Behavioral Sciences at the University of Washington. She is also director of the Behavioral Research and Therapy Clinics, a consortium of research projects developing new treatments and evaluating their efficacy for severely disordered and multi-diagnostic populations. She is also a Zen teacher in both the Diamond Sangha and in the Empty Cloud Sangha (Germany).

Dr. Linehan's primary research is in the application of behavioral models to suicidal behaviors, drug abuse, and Borderline Personality Disorder. She is also working to develop treatments which can effectively transfer from the research academy to the clinical community.

She has published extensively, including the clinically invaluable manuals: *Cognitive-Behavioral Treatment for the Borderline Personality Disordered* and *Skills Training Manual For Treating Borderline Personality Disorder*.

Dr. Linehan has received numerous awards recognizing her clinical and research contributions, including the Louis I. Dublin Award for Lifetime Achievement in the Field of Suicide and the Distinguished Scientist Award from the Society for a Science of Clinical Psychology (American Psychological Association). She also holds awards for Distinguished Research in Suicide (American Foundation of Suicide Prevention), as well as many other awards for her progressive work in the field of Psychology, suicide and self-harm prevention, and has

contributed greatly to the understanding of self-destructive behaviors. Dr. Linehan's most well-known theory and practice is referred to as "Dialectical Behavior Therapy" or DBT, and has been most successful at treating those who persistently commit self-harm.

Q. Thank you for being here today and freely contributing your expertise. Would you please tell us how you developed your theory of Dialectical Behavior Therapy and how you apply it?

A. Where I am now and where I began as a psychologist are very different. When I started practicing psychotherapy, behavior therapy and acceptance were two different things. At the time I began, in 1980, there really wasn't much information on distress tolerance or any focus on acceptance of circumstances to treat severely suicidal individuals.

I worked primarily with people who met the criteria of borderline personality disorder, though not all of my clients were diagnosed with it at that point. What became very clear to me immediately was that a technology of change without an associated approach that incorporated radical acceptance was doomed to failure. Indeed, it was failing. I knew I had to find a way to teach my patients how to accept lives of immeasurable tragedy and teach therapists how to accept their patients, as well as the often slow rate of progress.

At that time of my life I was very involved in Shalem, which is a spiritual development group in Washington, D.C. I was trained as a spiritual director working primarily with Christians. Indeed, I was doing some spiritual direction and education outside of my work.

Because of my background in Christian contemplative prayer, I knew that many spiritual practices emphasized acceptance, willingness, and surrender. Although I had studied and practiced in a contemplative tradition, for many reasons I could not find the acceptance I needed in my own life. I decided that if I could not do it, I obviously could not teach it. I would have to learn it first. I contacted all the people I knew in the contemplative tradition and asked for names of spiritual teachers. I went toward a spiritual tradition because I was looking for an approach that said you are "perfect as you are," rather than an approach that focused on change or one that implied you might need to change. This is why I do not do traditional Western psychology.

Even in an approach that offered unconditional love, the premise was that you were on your way to being fully actualized -- emphasized that you needed to change and were in the process of developmental change. I did not see how to translate Christianity into psychotherapy because it has too many spiritual constructs and words, and I needed an approach applicable to everyone. I am a Catholic. I am also a Zen teacher now. I surely was not a Zen teacher then. I had no idea whatsoever what Zen was. I am sure I had heard of it, but I did not know anything about it. What I really was looking for was a very good spiritual teacher.

Eventually I went to Shasta Abbey in California, where I stayed for three months. Next I met a Zen teacher who is also a Catholic priest, a man named Rev. Willigis Jäger Roshi. He was in the Benedictine order. It was a perfect combination for me. I was supposed to stay at his spiritual center (Haus St. Bendikt) for one month, but I took a leave of absence from my academic work to stay for three months.

Willigis taught both contemplative prayer and Zen. I would do one week of Zen meditation and one week of contemplative prayer.

I began this process of spiritual study in 1984-1985. Ultimately, I asked him to be my personal teacher and have been going back twice a year until very recently. I knew even within a month of being at Shasta Abbey that I had found what my patients needed and what I had been looking for myself. I went to Germany to continue my study and practice with my Zen/ contemplative teacher, Willigis

Jäger in Würzburg. I came back and thought I would teach all my patients sitting meditation, or *zazen*, which is really a large part of what you do in Zen, especially in *sesshins*, which are extended periods of sitting meditation. I thought I had found what was lacking in Western psychotherapy and was excited to share what I had learned.

I went on every *sesshin* offered. I was Haus St. Benedikt's first long-term guest. I followed my teacher wherever he went. I was just one of the crowd at the end of the line. I had never done anything like this and wasn't always sure of the correct forms that we were supposed to do during the various rituals. I would look to the person to the left of me and do whatever he or she did.

In my clinical practice some of the patients I currently work with are very functional, but many are not. I do a lot with groups. When you treat groups, you can't have one treatment for half the room and

another treatment for the other half. If some people can't do something, you can't have that activity as part of the program.

When I tried to get patients to take off their shoes and sit on cushions on the floor, I could not remember why you take off your shoes or why you sit on the floor, but that was what I had learned so I incorporated it into my treatment. I tried to get the clients to breathe during meditation. They often said they didn't "do" breathing. I said, "Okay, let's just walk down the hall." I turned around in the middle of the hall and two out of ten were behind me. I went back in and thought: "This is clearly not what I was being taught." Clearly too, my patients were as confused as I.

I went back to my prior learning experiences and asked myself and my teachers, "What is the essence here? What is it you are actually teaching?" It isn't just sitting. It is not just breathing. It is not focusing or counting your breath. It is not the eighteen billion practices of forms and rituals that are a part of many Zen traditions. It is really none of those. The question was: What was it?

The process was one of translating the meaning of Zen practice into terms that were relevant to the lives of the patients I worked with. I realized that what my patients needed were meaningful lives, and not to be expelled from therapy for *not* changing; for not immediately grasping what was needed in their lives. With this insight, I began developing the process of radical acceptance: living in the moment and discovering a way to accept the reality of what a life was without thinking that life had to be ended if it did not fit with one's expectations. More importantly, therapists had to learn how to accept the reality of their clients' expectations without feeling like failures, or that the clients were impossible when they did not see immediate change.

Q. Would you please discuss the meaning and implications of the concept of radical acceptance in your therapy?

A. Radical acceptance is complete and total openness to the facts of reality as it is, without throwing a tantrum or responding with willful self-destructive behaviors. It is not acceptance in order to get something to change, but total acceptance, from your toes to your head. Everyone needs to synthesize, to integrate into their deepest selves, the apparent contradiction of acceptance and change. The idea is not to accept everything as if you are

never going to change it. Hopefully one does not simply accept an abusive situation, believing that is true radical acceptance. Acceptance *is* change and change requires acceptance. You can't change something if you do not understand it and accept that it is what it is—reality without blinders on or excuses or pointless blame.

A car mechanic who refuses to accept that a car does not work or that there is something wrong with it would have a difficult time fixing it. However, the mechanic is not delusional. A mechanic's job is to find what is happening with the car, accept the reality of the car as it is, before it can be fixed.

I knew whatever they were teaching me was what my clients needed. I also knew this was what therapists need in order to work with a group of people who are essentially at high risk of suicide and self-harm.

Patients diagnosed with Borderline Personality Disorder could wind up dead at any point. They have a ten percent “success” rate of suicide completion. This is a very fragile and difficult population to work with. I never used the word “Zen” until very recently. I wanted a practice that was compatible with very far-right Christians, conservative born-again Christians, atheists, agnostics, Jewish people, Hindus, Buddhists—everyone. I was extraordinarily lucky to have found a teacher who is not only a Zen master and a Catholic priest, but is also committed to “trans-confessional practice,” as he would put it. That means strengthening a person's religion, if they have one, while at the same time having a spirituality that is compatible with all religions, including humanistic, atheist and agnostic, Catholic, Zen, Christian. This simply was a set of practices that were compatible with a person's religion or absence of religion. I was just lucky to have found a teacher who could teach in that manner.

Zen doesn't propose an independent self. Neither does behavioral therapy. Zen focuses on unity—that everything is connected to everything. Of course, behaviorists are constantly saying that you can never look at an individual independent of the context or a context independent of its population's content or behavior.

Behaviorists focus on the individual. Although integrated, you are still an individual. In a way, the whole Zen approach is compatible with the behavioral approach. Both focus on the present: what one is doing now.

What often arises in Zen teachings is the idea that it is the causes and conditions in an individual's life that create an individual's situation. It is similar to science: It requires close observation of the individual, and checking your observations with someone else, such as a teacher.

Q. Would you say that behaviorism is just stated in slightly different terms?

A. The good thing about Zen and behavioral science is that there is nothing incompatible between the two. Given that I was brought up Catholic, most of my heroines and heroes were the mystics. I was always drawn to the contemplative side of things. Zen is a mystical practice. That was very compatible with being Christian. It wasn't incompatible with anything else. All I had to do was find a way to talk about it. For a long time, I would (and still do) talk about it without using any spiritual terms. I used the term "wise mind," which is really based on the simple idea that all people have the capacity for wisdom. Of course, Zen would say all people are wise. I don't always say that to clients, because I would have to go into a whole explanation about how that could be true. I drop out the phrase "You are wise" and instead tell them that they all have the capacity for wisdom.

Meanwhile, knowing that in reality we all have wisdom, there is the "wise mind." The rest of the work is mostly trying to figure out what my clients have taught me about themselves. How can I break this down into ways people can put into a daily practice?

I translated meditation into behavioral practice. Also, Zen is a lot more than meditation practice. It is seeing ultimate reality just the way it is. That is enlightenment, just experiencing reality as it is, even if just for a split second, and then living one's life based on that experience. In many ways it is seeing reality, becoming reality, becoming one with reality, practicing becoming one integrated individual, while also being connected with everything else.

It is breaking down reality and mindfulness into ways that people can practice—practicing not being judgmental, which is without doubt the most radical change for most of us, far more radical than anything else. Once you get rid of the construct you are either good or bad, most people think, "What else is there?"

Zen is very radical. It is a lot more radical than people think.

Christianity is very radical, too. You have to let people go at their own pace.

Living in the moment, participating and using effectiveness skills, is the primary concept that came straight from Zen. Zen uses the term “expedient means”—skillful means. It is like once you are up on the flag post lost in that sense of joyous experiencing, you ultimately have to come down and go to the grocery store, get the groceries, and cook a meal.

That is the radical acceptance of reality we are discussing here. It is the willingness of turning the mind toward complete acceptance of things just as they are.

This concept of willingness came from Gerald May, who is a Christian, mystical writer, and a psychiatrist. He was the co-director of Shalem in Washington, D.C. His book, “Will and Spirit” is unbelievable. His discussion of willingness is just beautiful. In many ways, a lot of my work is taken from him.

Willingness is entering into reality as it is—the cosmos, the life of the universe—without grudge and without bitterness and participating fully. It is the opposite of trying to control everything, or of sitting on your hands and being passive.

It is really not much different than what is in Zen. It is just another way to frame it. Clients get it. They love the construct itself, because they can argue about who is being willful—you or them.

Q. Yes, it is very accessible. It feels that way to me when I read your material and compare it to my Zen training. Mindfulness is something that is so intimately connected with our actions.

A. I had to figure out what I was going to call this skill. You have to remember that when I started, “mindfulness” was not in common usage. The term was not something I had encountered very often in psychological literature. I needed a term that wasn’t Zen. Psychologists study mindfulness, whatever else they may choose to call it. That is an area that already has a research base to it. I also found an affinity for the 19th century German philosophers, Immanuel Kant, Georg Wilhelm Friedrich, and of course, Marx and Hegel, who examined the dialectical, or opposing forces, in all things. This was very compatible with Zen teachings of

the existence of both form and emptiness in all things. In other words, the process of the therapy I believed would be most helpful to the self-destructive was one synthesizing the opposites of acceptance and change, both from the patient's perspective and from the therapist's perspective.

The dialectical process and Zen's integration (or some would say "annihilation") of duality were both somewhat erudite and eclectically spiritual. I needed a term that was a psychological word that would not make people think I was doing something spiritual. That is how I came up with the word *mindfulness*. Then I read *The Miracle of Mindfulness* by Thich Nhat Hanh, and said, "Okay, this looks really good. I am going to use that word." Mindfulness wasn't in clinical psychology or psychotherapy at the time.

Q. You are very much a pioneer, integrating this.

A. The first person who pioneered this was Alan Marlatt in 1978 in the area of addictions. He did not use the word *mindfulness*. He did meditation. Later, in 1984, Jon Kabat-Zinn developed a mindfulness intervention for physical problems. I began in 1985. My work did not get published until later, but I was doing it in 1984-86. I was one of the first—if not *the* first—people in clinical psychology to use the term in psychological treatment. And the treatment became well-known.

Kabat-Zinn was the first to use the term *mindfulness*, but he applied it to medicine. Marlatt was the first to do a randomized trial using meditation. I learned a lot from Marlatt, who is at the University of Washington, as am I. I have become much more active in teaching mindfulness. I am leading many more retreats, both with my Zen teachers and by myself. I am now moving toward working with people who truly need the experience of connection with the universe, the reality of their own essential validity and essential "goodness." Although one can discuss the spirituality in superficial ways, people are drawn to those who are able to discuss deeper spiritual issues. I also include in my teaching simple mindfulness circle dancing.

Q. Is this at all like Sufi dancing?

A. No, the idea is to put people in a circle and do the very same

simple steps over and over, going around the circle. Ultimately, if you do it often enough, you suddenly start to experience that you are part of something beyond yourself. I work with patients who are the ultimate outsiders. None of them feels a part of anything.

In Zen, of course, the whole idea is there is no outside and there is no inside. You can't really be an outsider. Knowing that intellectually is one thing. Experiencing it is a totally different thing. At the moment, I am trying to develop strategies that would help people experience that. You will ultimately get there if you attend Zen retreats long enough.

Q. “Reality acceptance” sounds like practicing taking life on its own terms instead of trying to dictate the terms.

A. The central component of the whole thing is the concept of practice. I never tell anyone to simply accept something. I never say: “Accept that” or “You should radically accept this.” Such an attitude is almost always experienced as invalidating. All you can ever say to someone is “Practice”—practice mindfulness, practice meditation, practice self-awareness.

That is what my work is truly about. It is all constant practice. That is the most essential thing I have to say to people. The minute you tell a person to do something, then that is experienced almost inevitably as: “If you knew what I was going through, you would never say that.” When I say practice it, by implication I am saying we know this is hard. We know that to practice radical acceptance, to practice mindfulness, may be the most difficult thing you have ever had to do.

Practice is effective over time. It is especially useful to observe yourself practicing, to observe yourself being judgmental. I have been amazed at how people can practice anything. They can practice everything, but they can't DO everything. There is a great difference between practicing, allowing for mistakes but always returning to practicing, and trying to force oneself into acceptance.

Q. Thank you so much for talking with me. I know the readers of this interview would like to find out more about your work and studies. Where can they find your work?

A. I am in the process of writing about my most recent work. I have not written a book about mindfulness, but I ultimately will. There

will be a new version of my “Dialectical Behavior Therapy” skills book out soon. My dilemma is that I want to always stay tight with data and not give in to speculation.

On the reading list I give to people I work with is the work of Pat Hawk, with whom I am studying in Tucson. He originated the Pathless Path program in Arizona. I also recommend that people read Robert Aitken. If you know Bob Aitken, then you know me (although I do not believe I am as advanced as he is in the study of mindfulness). I have developed much of my theory from the 14th-century “Cloud of Unknowing.” That is the Christian side of mindfulness. I do three retreats a year now. That is really what I am moving toward, doing more retreats on Zen contemplative mindfulness. I do them for therapists. At some point, I may try doing them for clients. I doubt that I will do them for the general public. If you really want to find me, you need to find a retreat I am doing.

Q. Can people reach you through your University of Washington website?

A. Yes, for now my website is through the University of Washington: <http://depts.washington.edu/brtc/> .

NW. Again, thank you so much for your time and for providing such useful information. Your insights are truly invaluable for therapists and lay people, as well.



Florence Caplow

Riding the Horse of Change

Florence Caplow is a botanist and an ordained Zen priest. She has worked many years as a field botanist and, with fellow botanist Katy Beck, discovered two new species of plants several years ago in the Hanford Reach area of the state of Washington: the *Lesquerella tuplashensis*, commonly known as the White Bluffs Bladderpod and *Lomatium quintuplex*, or Umtanum Desert Parsley. She has most recently worked in the Department of Ecology for Washington State, although now spends the majority of her time writing and participating in Buddhist retreats. Her most recent publication is *Wildbranch: An Anthology of Nature, Environmental and Place-based Writings*, co-edited with Susan Cohen and published by University of Utah Press (2010).

Florence has practiced Zen meditation for many years and has lived for extended periods at both Tassajara and Green Gulch monastery, as well as in solitary retreats in the mountains above Muir Beach. At the time of this phone interview she referred to herself as a wanderer without a fixed place of home.

Q. You call yourself a wanderer. Where are you now?

A. I am at a little retreat cabin on the southern Washington coast. It is lovely and very sunny here today. I am sitting outside listening to bird songs as I talk with you.

Q. As a Zen priest, you teach meditation. In the past ten years you have also been very sick with an auto-immune disorder. Please tell us about your history with meditation as it relates to your illness.

A. I began with Vipassana meditation about twenty-three years ago. At that time I was healthy. What brought me to my meditation practice was a book by Steven Levine called *Who Dies*, which is quite an extraordinary book about death and dying. I was so affected by the book that I realized I really wanted to develop a meditation practice. That was the beginning. I actually still practice both Vipassana and Zen meditation.

Q. What is the difference between the two forms of meditation?

A. Vipassana developed in Southeast Asia based primarily on the earliest teachings of the Buddha. The form of meditation that people practice in the West is very similar to how monks and nuns still practice in Thailand, Burma, and Sri Lanka. Zen primarily was developed in China and Japan.

To be honest, in terms of my inner experience, when I am meditating it is always me, the true me, on the cushion. It doesn't matter if I am participating in a Vipassana retreat or a Zen retreat. They each have their own flavor. I love Zen practice for its beauty and poetry, but I have found that I can take better care of myself in Vipassana retreats.

There is more room for individual practice. Zen has an emphasis that came from a strong monastic tradition where everybody practiced together. In your retreat you become "one body." But it can be very difficult if you can't completely engage with the schedule. In a Vipassana retreat, I can create a different routine where it is possible to take care of the body. If I need to lie down I can lie down, or if I need to go out and be in the sunshine or whatever I might need in the moment, I can actually take care of it. It is an interesting balance for me. I still do both, but I love long silent retreats, a month to two months. That is



something that I can do in the Vipassana tradition and take care of my health at the same time.

In terms of the history of my illness, it started about ten years ago and went undiagnosed for quite a long time. It was eventually diagnosed as two different auto-immune disorders: auto-immune thyroid disease and connective tissue disease, which is in the same disease family as lupus. It involves periods of intense full body pain, nausea, and weakness, interspersed with times when I feel quite fine.

It is an interesting practice working with this illness because it is not a consistent difficulty. I never know when it is going to hit. When it does it is extremely painful and debilitating to the point that it is sometimes difficult even to take care of myself. One of the central features of Buddhism is impermanence. You could also see it as unpredictability, which is one of the characteristics of this illness. I have to dance with it.

Q. You wrote an article, “Dancing in Dark Fields,” which describes your illness as a dancing partner. That is a beautiful metaphor. Could you please say more about that?

A. The article was published in the spring 2009 issue of *Inquiring Mind*, the journal of the national Vipassana community. Essentially, before I got sick—and I think a lot of people who are healthy experience this—it felt like I could ride my body like a

horse. It was dependable. I could push it. I could make it do what I needed it to do.

Since the onset of my illness I have had to develop a radically different relationship with my body, which has taken a long time. Those habits of just expecting my body to do as I say were very deep, as they are for anyone who hasn't struggled with chronic illness. I had to learn to listen to my body very deeply, to honor it, to respect its needs, to not override the messages it was sending me.

When the illness is in full intensity, I feel like I have to treat my body as the lead dancer. I have to surrender. I was just in a short personal retreat with a friend and was thinking about how at any moment what we are given—both in terms of physical and mental conditions—is always the result of the past moments. What we are given is what we are given. What we do with it is up to us. But what we are given, how the mind or how the body is at any moment, is what IS happening.

I was in a fair amount of pain during this most recent retreat. My mind was all over the place. I had to remind myself: "Okay, my practice is not to fight this, but to understand that this is what is happening, and that the kindest thing I can do is to keep showing up, keep trying to be present for the moment." But I also had to remember to not fight the body and mind and the kind of conditions that arise. Conditions change. That is the nature of all conditions.

My condition changes sometimes more dramatically than other people's, but that is true for all of us from one moment to another. If the illness becomes my enemy or the body or the mind becomes my enemy, the current moment is going to be tremendously more difficult than it needs to be.

Q. Is it somewhat like being at war with yourself?

A. I think that I often feel that way, at war with the reality of the situation. I know I struggled with that, and with accepting the truth that I am not alone in this struggle.

Because of my own disease, I have experienced the challenge of listening to my body: the need to adopt sitting postures that are very different from the group, sometimes skipping a period of zazen in order to lie down or walk the stiffness out of my body, being, and feeling "different."

Q. How do you cope with these conflicted feelings when you practice zazen?

- A. Not everyone is at battle with their reality at all times or with their body. However, it is a common response, especially because it is difficult. We don't like it. We want it to go away. We want a different body, a different mind, a different experience at the moment.

Ironically it is an integral part of Zen to accept reality, just as it is.

Often I want that difference not to be there. How much I suffer depends on how hard I hold onto that rejection of reality. How strongly I hold on to the sense that it is unfair or shouldn't be this way in this particular moment will determine exactly how much I am suffering at that moment.

Q. Buddhism teaches that if you can completely accept reality just as it is (the fact that you are sick or that eventually you will lose a loved one, etc.); by accepting both the sorrows and the joys of life, then the quality of your life can change. For example, if you can stop trying to control everything around you and then feeling furious or depressed or impotent when you see how much of life is really out of your control, much of your worrying, your suffering will decrease and that such acceptance can be transformative. Have you found that to be true for you?

- A. There are different levels of suffering. The fact is physical suffering can be incredibly intense. Such pain can subsume all else if we allow it. For me it is important to recognize that there is a whole cascade of physiological and emotional responses to strong pain. This is the body's response to pain. Then there is our learned response to pain, how we interpret the sensations we are experiencing, judging them, and then reacting to those judgments. If we judge the sensations to be intolerable, we will experience them as intolerable. This is the "suffering of suffering," the second layer that we put on top of whatever baseline suffering we are experiencing only increases our distress.

Q. Are you saying that the “horrible” and “catastrophic” labels with which we interpret our pain may make us feel worse? That our cognitive thought processes can add whole new layers of suffering to the suffering?

A. I went to a month-long Vipassana retreat last winter and I was very sick. I knew that a lot of this retreat was going to be about exploring the illness and my relationship to it. I actually had this very significant moment of turning toward freedom in the middle of it. My symptoms were very strong.

This very traditional, very old Buddhist practice teaches us to recognize that at any moment, any sensory experience—seeing, feeling, hearing, smelling, tasting has one of three qualities. We have no control over these qualities, and they arise immediately with the experience. The qualities are (1) pleasant, (2) unpleasant, (3) neutral. It may also be that we can’t decide—that our experience is in between.

I found that I could either experience the pain as pain that I really desperately wanted to stop (there is a way I feel inside when I have tightened around the pain—clenched around it mentally and physically) or I could just note it as an unpleasant physical sensation. I know it sounds a little funny. What is the difference between saying, “Oh, I am in pain!” or “I have an unpleasant physical sensation that is arising right now.”?

But I experienced a radical difference between the two in terms of how free I felt in the middle of being in pain. Just to be able to know that it was unpleasant at that moment and that at the same moment there were also pleasant things happening. There was the beautiful sky in front of me or the feeling of sitting on a soft surface. There were many such things happening all at once. Some of them were pleasant, even wonderful. Some of them were unpleasant or even terrible. But they were all happening in that moment, not just the pain. I could choose what to attend to, and remember that all of it was impermanent, even the pain. Everything changes, even the pain.

One of the things that happens a lot with pain and illness of various kinds is that we tend to narrow the focus to this one really obvious thing that is happening and miss all the other things that are also happening. When I allow myself to be this big container where a whole range of things are happening and only one of them is this unpleasant physical sensation I am having—there is a kind of freedom there.

Q. How has your meditation practice helped you learn this way of looking at things?

- A. For me, meditation practice is deeply and intrinsically a part of my life. It has been with me for more than half my life. It is hard for me to imagine what I would be without it. It has changed many aspects of how I experience being alive. One of the major gifts of meditation practice is to see that things come and go. We have a choice about how we relate to a given moment. For a lot of people there is no sense of choice. In a way that is bondage.

What meditation can help with is to slow down. It is one of the reasons I do longer retreats in addition to my daily practice. I can slow way, way down and actually see that whole process of how I habitually react to certain things. Then I can see the possibility that there is a moment in there where I can perhaps—maybe not every moment, but occasionally—react in a fresh new way. When you realize that, you realize you have this possibility of freedom right in the middle of whatever is happening. Life does not have to be perfect in order to be joyful. That was a radical discovery for me.

Q. Not everybody can go away on long retreats, because they have a job or family. What would you advise for people who can't get out of their busy life, but still have to struggle with an illness, with the pain, with the daily reminder that their body is far from perfect?

- A. At this point in my life, as important as meditation is for me, one of the hardest things to do is to intentionally take time away from responsibilities, even if it is ten minutes a day. To actually stop and take care of oneself is so critical. Whether it is a walk alone or lying down and not having a radio or television on or not being in conversation, making time for yourself to be still and quiet can make a huge difference in how you respond later to all the demands in your life.

It is extraordinary how hard it is to create even small amounts of time in which we are not interactive and filled with whatever sense of responsibility we have. The kindest thing anybody can do for themselves is to find a way to have quiet time. Even ten minutes can make that crucial difference.

I have a young friend with Hodgkin's disease. She has begun a meditation practice and it is five minutes a day. That is as much as she can manage at this point. But those five minutes a day are changing her life. I see it in her. People sometimes have this idea that if they can't carve out twenty minutes a day or an hour a day for meditation practice, that there is no way to enter into it. The five minutes a day or whatever it is, is important as a way of saying, "I give this to my body and mind to be able to have a moment of real rest and silence." If that is all you give yourself that can be enough.

My experience is that if I don't have a little bit of time to be still, it is unlikely I am going to remember to be aware of what is happening through the rest of my day. That little bit of stillness is really almost like a homeopathic amount of stillness. It is really helpful. Sometimes reading about some of these ideas, which are pretty counter to our ordinary way of looking at things, can be really helpful.

Q. You wrote an article for the Buddhist magazine *Tricycle* about Michael Sawyer, who had Parkinson's. You quoted him as saying, "Everything is practice. I can't sit on the cushion anymore, but I am still practicing minute to minute." What was your experience with Michael?

A. Michael passed away over a year ago. It is always a great pleasure to talk about Michael. He was a great man. He was diagnosed with Parkinson's in his early forties, twenty-two years before he died. At the time of his diagnosis he was already a student of Zen, a resident at Green Gulch Zen Center in California, and a master carpenter. He was also a very talented painter.

I met Michael in the early to mid-nineties. At that point he had been diagnosed for a little less than ten years. He was already dealing strongly with the effects of Parkinson's. We really connected. At that point I was still healthy, but I had a friend that was very ill with a chronic illness. Michael ended up not only helping me to learn how to be a better friend to her, but he became a long-distance teacher for her as she learned how to work with severe illness.

Over the years I maintained contact with him. A few years ago I was spending some time with him and realized that he was absolutely one of the most inspiring people I had ever known. Everyone who knew him felt this way: I was not alone with this perspective. He had

this extraordinary thing where he turned the situation of his illness to the good, for himself and others. Three years ago he was no longer able to walk. He often couldn't speak. He was almost entirely confined to a hospital bed in a small room.

Somehow, in the midst of that, he was one of the most utterly alive people I have ever known. One of the reasons I wanted to write about him is that about that time—about three years ago—he said to me that the last five years had been the happiest years of his life. Here was this person who in the last five years had physically entered a time of his life of incredible limitation. Along with his own inner happiness, he managed to touch and inspire virtually anyone who came into contact with him.

You have to be careful with this. It is not that I want to set up an ideal of the saintly sick person. Michael wasn't saintly. He had his moments of huge frustration and deep grief over what was happening to him.

He didn't want to die. One of the reasons he talked about why the last five years had been so happy for him was because, as he could do less and less in the world, he had the time to paint. He spent the last five years of his life basically painting all the time. Even as his ability to do almost everything else disappeared, he could still paint. The paintings were wild, psychedelic Buddhist art. He experienced joy in that freedom to be able to fully express himself.

A lot of what he would talk about was the way we express ourselves all the time. Even when he could no longer paint during the last six months of his life he said, "We are always expressing ourselves. Every moment we have this opportunity to express who we are." He was this very genuine, alive person who never hid or lied about what he was experiencing. In a way, he gave everyone who came into contact with him the courage—whatever their circumstances were—to think about the journey we will all walk at one point or another into sickness and death. It is possible to do it with awareness and grace and a willingness to be completely alive, no matter what your circumstances are, until you are gone. I wasn't with him when he died, but I know the people who were. That was true of him right into his death. He was completely there. He was a hugely important teacher for me. That is the thing I always look at: what does it mean to live a life where you are willing to completely meet that life and be fully alive whatever is

happening? Sometimes what is happening is horrific. What was happening to him was horrific. He danced with it. He totally danced with it, every moment. It was amazing to watch.

Q. From what I have seen there is incredible detail in Michael's paintings. Did he have a tremor and, if so, did it interfere with his painting?

A. Those paintings span from the seventies to the late nineties. By 1999, he had definitely lost a lot of motor control. He said he couldn't understand it—how it was possible for him to paint when getting a spoon to his mouth was often not possible. He did paint up until six months before he died, and I have seen those paintings. There is less detail. His original paintings were so detailed you could see details with a magnifying glass that you couldn't see with a naked eye. As he was less able to do that very fine, incredible detail, he said everything got looser. There wasn't some kind of perfection that he was working everything. He did tons of erotic paintings. He was alive. He was fully alive.

He did not have a lot of tremor, but he did have a lot of motor control loss. One of the things that was sad for me was that because he was so limited in his mobility, even people who lived in the same community often didn't know him and didn't even know that he painted. Due to the need for bed rest and his limited mobility, he was hidden. His art was hidden. To me that was a tragedy. His work is powerful.

Q. Florence, you are currently writing a book about the journey through your own illness. Would you tell us a bit about it?

A. I have full-blown lupus, so I was really playing with fire by continuing to work full-time. I didn't know how it was going to progress, and I felt like there were some things I wanted to do with my life while I still could.

This is one of the roles that illness can play in our lives—to be a sword before us that reminds us we do not have forever. What really matters? I do hate the whole New Age “illness is gift” idea. That is a little strong.

I think about this when I think about Michael. He knew what was most important to him, which was his painting. Without the space

that illness created, he would have been out there working hard for his community and making things. There would not have been time for the painting.

I would be still working as a conservation biologist for the state of Washington if it wasn't for this illness. I asked for a year's unpaid leave from my job. I couldn't keep my house because I couldn't pay my mortgage if I didn't have a job. I sold my house and spent a year doing absolutely what was most important to me. In my life.

That kind of big move is not something that is possible or even appropriate for many people dealing with illness. I haven't done a lot of reading on this, but I have heard that some people who have studied cancer survivors have found that when people actually do the things that they have been putting off, do the things that most matter to them, their survivorship rate increases. It is good for our immune system to do what really brings us happiness. That is what the journey was and is for me: to be in alignment with what really matters in my life. I don't know how long I have to do those things. For me what matters is spending a lot of time in the mountains and deserts and on retreats and with friends.

That is what I wanted to write about. That is what the essays in my book are about. The essay on illness and the one about Michael are both from the book. The essays are about things I have learned from the journey. The book, *Slipping Glimpsers*, co-edited with Susan Cohen, published by the University of Utah Press. I began to write because I felt like I had seen something profound about illness I wanted to share. I also have essays about illness, nature and Zen practice on my own blog. I hope these writings inspire others to turn toward what really matters to them before it is too late.

Q. When you find yourself in a place where you are experiencing a lot of negative thoughts, how do you transform that?

A. One of the things I learned early on in meditation practice is that no amount of will or desire will make something that is happening in the mind go away. In fact, the greater the will that is applied to it, the more you focus on it, and a certain dynamic gets set up whereby that negative thought gets stronger. When that is happening, I find what is most powerful is to recognize that it is happening. Recognize the thought with as little judgment of it as

possible. A teacher I know has beautiful ways of putting this. She suggests that you say to yourself:

Ah, fear is like this. This is what fear feels like and sounds like in the mind.

Ah, this is what anger feels like, this is what despair feels like.

This is not about trying to make the negative thinking go away. It is simply recognizing what is there as gently and compassionately as possible. Feelings are definitely more likely to transform or change if I'm not in a battle with them.

You are looking at it more calmly, almost objectively, yet also seeing it as an integral part of yourself. There is not that overlay of panic. You just stay with it.

At a retreat I attended some time ago, for some reason, I was utterly heavy-hearted. There was a weight on my heart of all the grief, all the sorrow. It didn't go away. As it continued and as I looked at it, I realized that I could be brave and compassionate in the face of my own sorrow. It was not going away. The more I could open to what I was feeling and care for myself in the middle of it, the greater the likelihood I could do it for someone else. It would make it more possible for me not to run away from the suffering of someone else. Part of the reason we cringe or turn away from someone who is suffering is because we are not comfortable with that suffering. We are not comfortable with what it evokes in us. It could happen to us. As a person who feels as I do, I do not want to turn away from other people's suffering. In that retreat I realized that as much as I did not like what was happening, whatever I could learn from it would make it more likely that I would keep my steadiness and love and compassion open in the face of suffering in the world.

Psychologists might call this *reframing*. Instead of this being MY terrible suffering, I say: "OK, I don't know why it is happening, but if I can learn to practice compassion and openness and kindness, this will benefit other people in the future." I find this perspective helpful and feel it has had that positive effect.

I felt like I was the brave hero, facing the wounds of the world in my own heart. I never understood why it arose. It dissipated soon after I left the retreat. It was one of those mysterious things. You don't know why some things come up in your mind. That *reframing* of difficulty

can be true for all of us—that was just the form it took for me—one of the ways to find a new relationship with difficulty.

Kindness toward oneself is an under-appreciated value. We sometimes think in this culture that to be kind to the self is self indulgence. Yet to consciously practice kindness toward yourself—the way you would toward a child who is ill—is one of the greatest gifts you can give yourself. It has to be learned because, unfortunately, a lot of us haven't learned it culturally.

Q. We say: “Other people have it worse. It is not that bad. I shouldn't complain.” We are often told to ignore our own pain and suffering. Suck it up. How do you cope with such cultural responses?

A. There are times I just lie on the floor and cry. It is hard. That is actually compassion to myself to recognize: “This is really hard, this affects my life very deeply.” It does take unlearning some of what we have learned to be able to practice that kind of kindness toward ourselves. It is really, really important.

NW: Thank you, Florence, for sharing your experiences with us. You truly have transformed what could be an overwhelmingly defeating illness into a life-giving, compassionate experience. You have offered through your thoughts and writings a deeper look into the transformative power of mindfully experiencing one's own life.

Florence's blog is <http://zenshin-edz.blogspot.com/>





J. Lee Nelson, MD

The Zen of Medical Research

Dr. J. Lee Nelson is a Member of the Fred Hutchinson Cancer Research Center and a Professor of Medicine at the University of Washington School of Medicine. She has practiced Zen meditation for many years and was recently given Lay Entrustment by her teacher, Norman Fischer, certifying her as a Lay Zen Teacher.

Q. Lee, could you tell us a little about your current research into autoimmune disorders?

A. Autoimmune diseases are traditionally thought of as diseases in which a person's immune cells attack his or her own body. There are many different types of autoimmune diseases. Our research has focused primarily on scleroderma and rheumatoid arthritis although we have studied lupus, insulin-dependent diabetes and multiple sclerosis to a lesser extent. In more recent years we have extended our work to some other diseases that are not autoimmune, including cancer.

Q. You are not only a researcher and scientist. You are also a Zen teacher and have been meditating for quite a long time—twenty some years?

A. Longer—more than thirty-five years. My desire to become a physician first arose after returning from a trip to India. The intensity of physical suffering that was so visible in India was very moving to me. I decided to go to medical school to try and do something to ease physical suffering.

Q. You have practiced in both the Vipassanā and the Zen tradition?

A. Yes, but my initial and primary practice has always been in the Zen tradition. I first found a Zen Buddhist priest to provide me instruction in Zen meditation in 1974, at the same time that I began medical school. I have kept up this practice since then. In more recent years, I have also practiced with a Vipassanā group that is close to where I live and work, but Zen is my primary tradition.

Q. Do you think your meditation influences your medical research efforts to advance and develop new treatment approaches for chronic illness?

A. Yes, however, I did not begin meditation with the purpose of trying to do something for my career. Ideas and insights sometimes occur during or after meditation. Even when this does not occur temporally related to formal meditation, I think the practice has been beneficial to my work in a number of ways.

For example, meditation can help cultivate a wider perspective and make it easier to see when we are getting stuck in our opinions. The heart-to-heart connection with other living beings deepens and this is also a major motivation for my work. There is an aspect of spaciousness to meditation practice that may impart an openness to insight.

On the other hand, I also need to do the work of intently studying the subjects related to our research work. Once I have done this, I often walk away from it for a while. Sometimes when meditating or after meditating, insights occur and it becomes apparent how different pieces of information connect. Yes, I do the work. But there is

an aspect of being open that I think can help allow the pieces of a puzzle to come together. If there is only continuous addition of more and more information there may be less room for insight.

Q. You recently published a paper in *Scientific American* providing an overview of work being done in the field of microchimerism. Could you tell us about this field and the work you are currently doing in your lab?

A. The word microchimerism derives from the word “chimera,” which in mythology was a creature that was part lion, part goat and part serpent. In medicine the term refers to harboring cells that originated in another individual, and microchimerism means a small number of these cells. Some cells are exchanged between a mother and child during pregnancy and the exchanged cells persist in the other person decades later. Even when we are adults, most of us have a small population of cells in us that we acquired from our mothers during our fetal life.

Similarly, women who previously had a pregnancy have cells many years later that were acquired from the fetus. If a woman has a grown son, for example, we can draw her blood today and, if we look hard enough, find an occasional male cell. I use this as an example, not because there is a difference in having sons or daughters, but just because it is not difficult to see a male cell among female cells. It is interesting that, in a biological way, we are more connected than perhaps we used to think we were.

We first began to study microchimerism in scleroderma. Scleroderma is a disease that is considered to be autoimmune, but looks strikingly similar to a disease known to be caused by foreign cells, called graft-versus-host-disease. Graft-versus-host disease is a complication of stem cell transplantation (previously called bone marrow transplantation) that occurs when the donor’s cells attack the tissues of the recipient.

Whereas scleroderma is traditionally classified as “autoimmune” we proposed that foreign cells, acquired from fetal-maternal cell exchange during pregnancy, play a role in scleroderma. Scleroderma has a predilection for women, especially in post-reproductive years. So we studied women with scleroderma and healthy women and found higher levels of persisting fetal cells in women who had developed scleroderma.

Additionally, we studied a particular set of genes that are important for the immune system and found a difference in these genes for children compared to their mothers, according to whether the mother had or had not developed scleroderma. Thus for scleroderma we think microchimerism is part of the problem.

Nevertheless, we currently believe it is likely that the benefits of the exchanged cells outweigh the less common disadvantages. In another autoimmune disease, rheumatoid arthritis, the research points to a beneficial effect of cells acquired from the fetus. There is a decreased risk of developing rheumatoid arthritis for women who have had children. Also, women who have rheumatoid arthritis and become pregnant often experience temporary disappearance of their disease during pregnancy but recurrence after delivery.

A colleague of mine once said to me “perhaps you should consider the placenta as a selective immigration policy.” I think this is a good metaphor. Now the field has really opened up. We don’t yet know all the consequences of the immigrant cells, but we think the cells probably have a wide breadth of beneficial effects but also sometimes adverse effects.

Q. Could you describe scleroderma?

A. The word “sclero” means hard and “derma” means skin; this expresses the hallmark feature of the disease, which is hardened skin. The skin hardening starts peripherally and moves centrally on the body, often resulting in contractures, sometimes ulcers and even loss of fingers and toes. Importantly, this same hardening process moves to the internal organs including the gut, lungs and sometimes the heart and kidney. One of the reasons I started to work on scleroderma is the prognosis can be worse than some forms of cancer and there is no known treatment that effectively and reliably alters the course of disease. It can be a deadly disease.

Q. Is it deadlier than rheumatoid arthritis?

A. We have fewer treatment options for scleroderma than for rheumatoid arthritis and this is especially a problem for the more severe form of the disease. There is a limited and a diffuse subtype of scleroderma that differs by the amount of skin and internal organ involvement. We have more treatment options than we

had ten years ago for symptoms and some of the complications of scleroderma. But, we do not have treatment that will reliably halt the typical lung disease that occurs with diffuse scleroderma. Really, what we would like to see is a cure. A number of different treatment approaches are being investigated now. Some people hope that stem cell research, once it takes off, could eventually help or even heal their condition.

Q. Is stem cell research going to help an adult who has a chronic illness, such as scleroderma, rheumatoid arthritis or Parkinson's?

- A. There are treatment protocols in the United States and in Europe that offer stem cell transplantation, previously called bone marrow transplantation, for some severe autoimmune diseases. The most frequent approach is what is called autologous stem cell transplantation. The word autologous means your own cells are harvested and after processing are given back to you.

The processing involves enriching for stem cells and depleting many of the mature immune cells that are thought to cause the disease. Stem cells can give rise to many different cells types and the theory is you will then recreate your cell populations from the enriched stem cells and won't repopulate with the bad cells that caused the disease.

I was skeptical that autologous stem cell transplantation would work for a disease like scleroderma when it was first tried. But the results from Europe and the United States look pretty good. Many people experience prolonged relief and even remission from their disease. Having a stem cell transplant is, of course, a very serious undertaking.

Q. It sounds exciting and having an autoimmune disease myself, my reaction is: "Wow! Where can I get that treatment?" Is it very limited at this time?

- A. It is available on research protocols at a number of different centers across the United States for some diseases. Severe scleroderma is one of the diseases for which there is this type of treatment trial. A few rheumatoid arthritis patients have had the treatment, but it is infrequently offered for rheumatoid arthritis.

Another disease for which this approach is being tried is multiple

sclerosis. Multiple sclerosis is an autoimmune neurological disease. I don't think this type of approach is being used for Parkinson's, which is also a neurological disease that is not thought to be autoimmune, but I think other types of stem cell transplantation are being studied for Parkinson's disease.

Q. I have heard various politicians and different factions in the population say stem cell research is bad – that it is against nature, against God's will. Have you run into any of that or is it no longer considered something scary and bad?

A. I think here we are talking about a different kind of stem cell research.

Q. I suppose that I am referring to the controversy about fetal cells.

A. None of our work involves embryonic tissue, which is the primary source of controversy. It's not an easy subject. An individual has to deal with their own belief systems and level of comfort, as well as the particular situation. If the issue came up for our work I think my decision would be based on the particular situation. I try to ask what can be done to alleviate suffering and what the best approach is while doing the least harm. I don't see an intrinsic problem with using stem cells in research. On the other hand, I can imagine particular situations that would pose a dilemma and others where I would say no.

When considering the most benefit and the least harm in medical research the issue of experiments with animals is another one that elicits strong feelings. A number of years ago I was attending a meeting where a colleague who had created an elegant mouse model for scleroderma was giving a major talk. In the course of a conversation with him he said: "You know, the older I get, the harder it is for me to kill the mice." It was very sweet as what I understood him to be saying was that, as he recognized his own mortality, he had come to deeper feelings about what it meant to sacrifice an animal's life.

There is no doubt that very important advances have been made working with experimental animal models. If a researcher concludes the best or only way to answer a question is in experiments with

animals, I would hope every effort would be made to be respectful of the animals. The animals cannot tell us they are suffering, but we can see suffering in animals, as is apparent when we see a pet react to injury or illness or when we have lost a pet.

Q. When I think back to the graduate lab where I worked and how I killed many mice in the name of science, I want to say now, “Thank you for sacrificing yourself and allowing us to better understand the effects of certain chemicals on different systems in the body.” Each time a new medicine comes out, I feel as if, somewhere along the line, an animal has been experimented on with medicine. Is that correct to say?

A. The extent of experimental studies with animals is variable. Some experiments are designed to try and understand what causes a disease. Others are designed to try treatments or intervention. I appreciate what you say about having gratitude and being respectful, not cavalier.

Q. If we were to move toward more human models, do you think people would volunteer to try something very new that may be risky? Have you asked humans to volunteer for your studies?

A. A great deal of progress can be made in studies with human volunteers with very minimal or no risk. Our research is focused on understanding the root cause of the diseases we study and we do not conduct treatment trials. With treatment trials there can be more substantial risk. However, depending upon the type of disease and response to conventional treatment, a person could be fortunate to have the opportunity to participate in a new treatment trial. For example, with some types of cancer a new treatment trial may be the best hope.

I think that a team approach that includes patients, patient-advocates, physicians and researchers can be a powerful way to move medical research forward. A few years ago I was visiting European colleagues and learned that the German government was specifically supporting centers where the research effort involved a team with a medical research group, a lay activist group for the specific disease and full-time practicing physicians caring for patients with the disease.

The government-funded program supported the whole spectrum of people so they could work together. With this kind of cooperative effort we can have a good chance of making advances in understanding and treatment options in our lifetimes.

There can be a tendency for scientists to migrate toward experimental animal models because it is easier and there is so much more that is under your control. You can order a certain type of mouse strain and have far greater options for experimental intervention. The important issue that arises, however, is how does this apply to humans? This question is especially relevant in my area of work where there are very substantial differences between humans and mice. I start from the position: Can I ask the question in studies of humans? It is not easy, but it is doable.

It is not difficult for a person to give a blood sample and there is a lot that can be learned from blood. It can be more challenging to study internal organs. However, often times there will be excess tissue available when someone has had a biopsy as part of their health care. For example, with liver disease, a biopsy is often done to figure out what type of liver disease is present. After the pathologist has studied the sample there is usually some left over and a person can simply say they are willing to donate the leftover excess for research. We can look at an internal organ from the species we are trying to help and this type of participation can make a big difference in moving medical research forward. We do not have the potential limitation of spending five or ten years working on a problem using animals and then maybe discovering the work has no significant application to humans.

Q. I have donated my blood to you and you have gathered DNA from my mother for your research. It was not a terribly intrusive process.

A. Some people do not like to have their blood drawn, but it is not a big procedure and there is really not much risk. I have heard family members say that it makes their heart happy to contribute in any way they can that might lead to helping people who have the disease their loved one suffers from. DNA technology has also made participation in medical research easier.

With DNA technology some studies can be done without even needing a blood sample; instead a saliva sample or cheek swab sample



can be sufficient. When I started out in medical research we didn't have DNA technology and we sometimes needed to ask children to give a blood sample. You can imagine what that was like, asking a child to give a blood sample. But it was moving to hear a child say "I am afraid to have my blood drawn but if there is anything I can do to help my mommy I will do it."

Q. Lee, as a scientist, do you think that autoimmune diseases are related to food allergies or any type of allergy? Or is it clearly genetic?

A. The predominant current view is that autoimmune diseases are multifactorial in causation. It is as if you are dealt a hand of cards and it is the combination of cards; in other words, a constellation of risk factors that adds up. Genetics is one risk factor that can have a greater or lesser contribution depending on the disease.

Celiac disease is an example of a disease where a specific food intolerance, to gluten, is known to play an important role. In a disease like rheumatoid arthritis it seems unlikely that changing what you eat is going to be a significant answer for most people. Rheumatoid arthritis

affects populations worldwide where diets vary markedly, the USA, Japan, China, Africa, etc., and it would be difficult to conceive of how food would be a major contributor to a disease such as this. That said, most of the autoimmune diseases exist on a spectrum and maybe within that diversity there are people who experience a difference if they change their diet. If there is something in your control you can do, even if it helps a little bit, this is good.

It is not unreasonable to work with and try out alternative approaches, as long as it is not something harmful. I would not personally put a lot of stake in the hope that changing a diet would be curative or be a major modulating factor. For my part, I have chosen to try and find effective treatment and/or cures for some of these diseases.

Q. You noted that meditation clears your mind to be receptive to insights that you can use in your research. Do you think that people who are physically uncomfortable, who cannot sit in a lotus-type posture, can still use meditation as a way to cope and feel that sense of clarity of thought and hopefulness?

A. Yes I definitely do. Regardless of how you meditate, even if you are lying down and meditating, it opens up a freedom and an understanding.

When you feel badly, there can be a tendency to identify with the suffering, to feel that is all there is. In meditation the intuitive knowledge that there is more than the suffering is more apparent. You may develop a certain detachment from the suffering. Meditation has been extremely valuable in my life. It has not made all aspects of my life easier, however. For example, after I began meditation while in medical school I thought my mind would be calm and all would be easier.

Yes meditation has been beneficial and invaluable. I could be in a very difficult situation in an intensive care unit with distraught families and when someone was dying, and I think I was better able to hear both what was being said and what was not being said. My heart was there with the patients, friends and family. At the same time, I wonder if my meditation practice resulted in less denial and less blocking out of pain, and so enhanced my sensitivity to suffering.

Meditation doesn't give immunity to sadness and pain. It can show a way to freedom beyond suffering and give a lot of strength. A key is



Dr. Lee “gets out of her head” for awhile

to accept pain and loss as is, without adding more or getting caught up in a narrative about the pain.

I think that it is important when taking up meditation seriously to work with a teacher or with someone who has experience. Then, when you hit that bump where you feel overwhelmed, for example with sensitivity, you have someone to talk with and help you through.

Sensitivity and empathy for the pain of others is a significant issue for caregivers. A loved one’s pain can be very difficult for the caregiver. We can feel almost more helpless. You love this person. What can you do? You want to make it better. You can’t make it better. Having a meditation practice can be very helpful for the caregiver.

Meditation strips away all the extra stuff that comes with suffering: the judgment of suffering; the fear of suffering; the “Gee—why me?” You can look at it as: “Okay, yes, this is suffering. Everyone suffers.” We can live with it without letting it define us. For me, meditation has brought some clarity and calmness around pain that I experience and my feelings about the pain that others suffer. When we simply

acknowledge that illness and death happen, there can be an amazing calmness and clarity. The pain is still there but it is not as frightening.

Q. Lee, in your experience, would it be helpful to hold a visual while meditating?

A. In Zen meditation the practice is to let thoughts, images, ideas, and feelings just come and let them go without adding a “story line” rather than holding a particular focus such as a visual image.

I don’t know a lot about practicing visualization but my sister who is a therapist and who has a meditation practice has said visualization techniques can be very helpful. I tried out a visualization exercise she recommended to me during a difficult time I was going through a few years ago and found it to be useful. I also remember her saying: “Okay, take ten minutes. Ground yourself. Sit down or go out for a walk so that you are not totally in your head.”

Q. I have worked with some of my therapy patients to help them focus on an idea or a picture of themselves as being calm and relaxed. Visualizing a setting, especially for very anxious people, can be helpful. I work with a lot of anxiety disorders. Having a guided meditation can help patients put themselves in a place where they feel safe and warm and relaxed. I do not have a set formula other than to work back and forth with patients to see what works for them. It is a bit like hypnosis. I am aware it is not Zen meditation.

A. It makes sense what you describe and that the usefulness of visualized images are particular to each person—whatever helps them feel safe, calm and is most appealing. The exercise my sister suggested to me was to visualize going down 10 stair steps one at a time and at the bottom to visualize arriving at a safe place, that felt comforting and relaxing. It is a kind of meditation. It is not Zen, but can be helpful.

I also like the Vipassanā tradition where they say: *May I be at ease. May I be well. May I be safe. May I be happy. May I be peaceful. May I be filled with loving-kindness.* These same phrases can be said for others. While not visual, these phrases are another practice that can be beneficial.

Q. Some people say, “I have a hard time meditating, but I say a daily healing mantra in a quiet time.” Does that accomplish the same goal?

A. We are diverse people and for some of us sitting meditation may be more difficult. It wasn't easy for me in the beginning. I was easily distracted and can imagine what it is like to experience ADD (Attention Deficit Disorder). I think that saying a healing mantra may be helpful. It does differ from shikan taza, which is the name for meditation as practiced in Soto Zen.

Q. Another question I am sometimes asked is about using relaxation and guided imagery CDs. Do you think that has the same effect as just meditating on one's own?

A. I think there can be benefits from listening to guided imagery recordings although this practice differs from Zen meditation. It is important to add that meditation does not require sitting in a traditional posture, for example full lotus, but can be done in a chair, lying down, whatever is most comfortable. What you want is to allow your mind to empty rather than put something into it.

Nonetheless, depending on what is going on for a person at a particular time point, listening to recordings may help for relaxation, to give the body comfort, or give the mind timeout, and if so it is all to the good. There are times when I use music to settle myself or listen to recorded talks. I have so much to do. I tune in to a talk from Norman Fischer and remember: “Wait a minute. I have the ability to pull myself back to being present and centered.”

One thing to add is that I think it is useful to connect up with a friend, a small group and/or a teacher. I find that I often settle down and am quieter faster when sitting with a group than sitting by myself. The cooperative effort can also support a healthy discipline.

Q. Our world keeps offering more and more options for people to help their distress, to get relief from their symptoms, to hope for a cure. People are overloaded with advice and often overwhelmed by the number of “remedies” offered to them. Why should someone try anything if it is not a guaranteed cure?

- A. We are living in an age of information overload. The world of medical research can feel like overload too. It can be overwhelming. There is too much to read and too much to know.

I try to begin by accepting that there is always more that can be known, that I have the limits of one human being, and that there is real hope for progress and better treatment of the diseases that I study. There are few options that can be considered a cure and not much that is guaranteed. It seems to be important to both seek expert advice and to take personal responsibility at the same time.

Q. What would you say to someone who once had a vigorous successful life, and is profoundly hindered by the sudden onset of a disabling disease?

- A. That person is not alone. Each of us will come eventually to death and many of us to disability along the way. She or he is just heading there on a time frame and with a problem she or he never expected.

It is difficult in a society that tends to make judgments of worth and seems to ask: "What did you accomplish?" Even just retiring after you have been measuring things by your accomplishments can lead to asking: "What is the meaning to my life now? I am no longer making this contribution by taking care of people as a counselor or as a medical professional. I am no longer helping with people's problems or household needs."

The mind wants to judge us that way: "I am worthwhile because of what I got done." But we can all think of people who are worthwhile to us not because of what they have accomplished, but because of who they are. I think we over-focus on accomplishment. We think of success as constructing something or leaving something behind with our name on it, yet accomplishment can be just opening your heart with loving-kindness.

Q. I agree completely. I am basically afraid of retiring because I have much of this mind-centered sense of "What am I accomplishing?"

- A. Recently I was reading in a book about waking up, in the sense of becoming completely alive in the present moment, to the sound

of a bird. You cannot put that on a score sheet. It is a whole other fully worthwhile aspect of beauty and life.

Q. Lee, I want to thank you so much for taking the time to share with us how you see the integration, the mutual interdependency, of medical science and meditation. Is there a way that people can read more about your work?

A. We have created a website www.microchimerism.org that provides an overall view of microchimerism research by ourselves and others. We also have a website for our research group which is <http://labs.fhcrc.org/lnelson/>. Thank you Nancy for your idea to put this book together and for your time, effort and caring in doing so.





Sandy Taylor

A Life's Work of Caring

Sandy Taylor is a Zen priest ordained in the Soto lineage of Suzuki Roshi. Having retired from a long career as a broker with the prestigious international brokerage firm of Smith Barney, she has trained as a minister to the sick, served for many years on the board of directors of San Francisco Zen Center, was ordained as a Zen priest and started a new meditation sangha in Seattle before returning to the Bay area. She has a family member who struggles with an emotional illness who she cares for in many ways, and Sandy herself has experienced breast cancer. She continues to practice Zen meditation and teach the Dharma in the San Francisco area.

Q. How has meditation helped with two significant challenges in your life: your breast cancer and your loved one's serious mental illness?

A. I think the worst part of the cancer was the treatments. The radiation was very debilitating, although I suffered the first big medical crisis when I was first diagnosed with breast cancer. I had to ask myself, "What happened? How am I supposed to respond?" When the doctor tells you that you have... whatever...

the first reaction is typically: “Why me? Other people get cancer. Not me.”

Then, obviously, it is me, or you, or someone else you may know; and you suddenly realize that you have never considered the reality we all must face ultimately: mortality—the mortality of yourself and those dear to you.

The reality of the crisis really sets in and then the other attendant issues arise. The most critical issue in the case of cancer is the problem of not knowing: Is the surgery going to get it all? Will it recur? What are the chances? What are the treatments? How is this going to change my life?

I was very lucky. I did not have to have chemotherapy. I was treated with radiation only. But people react differently to different medical treatments, and I felt incredibly fatigued from the radiation. The irony was that I had just taken early retirement and had a whole new life ahead of me. I had activities I longed to do, hoped to do, *planned* to do now that I finally had the time. Such a diagnosis certainly doesn't help one to maintain the equanimity so often talked of as a benefit with Zen practice.

Uncertainty sets in: Am I going to die now? Or, is the cancer going to come back, and if so, how will it manifest? When? What is in store for me? How am I going to react? What will it do to me? None of these questions, of course, can be answered. It was a little scary because I had cancer in my left breast and radiation was directed there, which is of course right over the heart. That is not good.

I wasn't ordained at the time, but I had meditated and practiced Zen Buddhism for a number of years prior to the diagnosis. That did help me remain somewhat more centered than I might have been otherwise.

Q. Those unknowns truly speak to the Zen teachings.

A. Yes, they do, especially the teaching of impermanence. The five remembrances in Buddhist literature are immutable facts in the case of serious illness. Ultimately, our bodies will break down and die. People often say, “I am going to die someday, but let's just focus on right now.” With cancer, the teachings of illness and death are unavoidable.

There is something unique to Western culture and certainly in the United States. Our culture is focused on youth. Keep your youth and always look great in a size six dress or bikini. I believe that such focus is true avoidance behavior. We don't talk about death. At the same time, we all expect to die. We don't talk about it, but it is there, lurking around as we grow older, or see our friends and loved ones die. Still, the majority of our cultural practices involve avoidance of death and uncertainty.

When something happens: a crisis such as cancer or the suffering of my daughter, who is extremely bi-polar, we all seem to be completely shocked. Again and again we ask the universe: Why me? What did I do to deserve this? We often believe that we are the exceptions, and that bad things should not happen to us. We become distressed, even despondent.

That is why breathing is so important in meditation, even if one isn't a Buddhist. It tends to calm the mind. Calming the mind restores the ability to see with clarity what is happening in our lives. It has an anchoring effect. It produces a sense of stability even in the middle of a crisis. It is not a cure. It is not going to cure the cancer. It is not going to cure my daughter's mental instability. But it will provide a stability, a way of coping.

The most important aspect of breathing deeply and not allowing thoughts to clutter your mind—they do, but you acknowledge them and let them go—is that it helps you to listen. Listening to yourself, to your body, is critical. Certainly in the treatment of cancer, I found that in meditation I was listening to my body, listening intensely. I can't emphasize that enough. When my body told me that I was really tired, I would go to bed. Part of restoration for any physical ailment is listening to your body, paying attention, and doing what your body says.

It is very well known that if a patient doesn't help themselves to get better, medicine can only go so far. This is true for all diseases. Doctor after doctor will testify that you have to help: *you have to help the doctor and you have to help yourself*. Meditation helps you to do that through breathing and clearing the mind, which in turn helps you listen to your body and pay attention to what it needs, to what *you* need to feel better.

In today's society, we also have this belief that faster is better. We multitask. Everything is go-go-go. That can be is very self-destructive.

Meditation can help you to slow down. I don't mean that in a negative way. It helps you to gain perspective on your crisis and to see where you are.

Q. Multitasking is rather the antithesis of meditation. Yet there are times when we have to focus on more than one thing.

When you are dealing with your own health, as well as your family member, as well as your daily life, how does meditation help you?

A. It helped me to say **no** to certain things. I naturally have very high energy. I always seem to be happiest if I have an endless list of "to do" things. I love it. What I realized is that I couldn't do it all. I had to make some choices about tasks on that list. I had to learn to say: "Tough, I just can't do this or that right now."

Q. What a wonderful freedom to be able to say no when you are so used to saying, "Sure, bring it on! I can do it all." Would you be comfortable sharing about your role as a care giver for your family member?

A. I have to say it is still very painful for me. This is a young person who had it all: looks, energy, bright as can be, and enormously talented and creative. There was a period where she was doing ceramics and she destroyed them. She did save one perfectly beautiful, very Japanese-looking tall vase, which she gave to me. I treasure it. It is the only piece left from that creative period in her life. She also painted and destroyed/slashed the paintings.

Q. Such energy to destroy sounds like she may have been manic, yet destroying her own beautiful works sounds so sad.

A. It is hard for me to know if this happened when she was in manic phase. It was very early on, when her behavior started swinging from manic states to depression. She expressed a lot of anger. She did try to help herself. She was convinced that she was an alcoholic and went to AA. She drank excessively, to a point where she was a falling down drunk. Then she realized that she really wasn't alcoholic, but was self-medicating.

She did go to see a psychiatrist and she tried prescribed medication for a while. This was a long process over a number of years. It is not like one month this and the next month that, kind of thing. The ultimate reality is that she had swung so many times into a manic phase, she seemed like she didn't want to stop. That is a form of addiction. Anyone who knows anything about bipolar disorder knows that a person who is bipolar frequently refuses to take medicine because it levels them out. They love those highs. Her behavior over years became more and more extreme.

I tried to help her, of course. The effect was that I was unwittingly enabling her. I so often felt in between a rock and a hard place.

Q. Sometimes when one is a very serious meditator, other people in the family—partners, kids—become interested in it. Did this person ever become interested in meditation? Did she ever try it?

A. She did try meditating at times, but did not like it because it calms you down, right? A number of years ago I took her to a beautiful meditation retreat center out of the country. She sat for a couple of times—we were there for a week—but she mostly refused to participate. She liked being there. She would swim and meet people and talk to them. But for all practical purposes, she would not participate.

Q. Had she already been diagnosed?

A. Yes. It was maybe seven or eight years ago. She told me on that trip that she was taking lithium, which is a standard medication for bipolar disorder.

Q. Yes, lithium is a mood stabilizer. Mark Epstein is a psychiatrist who incorporates Zen meditation into his psychiatry. In his books on Zen and psychology, he talks about how meditation is not the first step with mental illness. It may actually exacerbate the condition by opening up places within yourself you are not ready to see or feel.

A. I believe that is one of the responsibilities of being a Zen priest. I have a small sitting group in Seattle. One of a priest's



responsibilities in a sangha is to pay attention to the group. It isn't that one looks for trouble or imbalance in personalities, but it is important to be alert. Listening. Observing.

I had a case of someone who was stalking another person in the sangha. Thankfully it is resolved, but a participant's mental stability is something that we need to look out for before we go on a long retreat. The priest or guide for the retreat needs to ask tough questions sometimes: Are you on medi-

cations for any kind of mental disorder or mental imbalance? Do you have a serious mental illness?

People I know in San Francisco at the Zen center are very aware of that possibility. Some people are turned away. They exhibit behavior that can have very serious effects on themselves and may even bring out psychotic behavior in others.

Q. You must have trusted that your loved one was aware enough to know how to handle meditation if you brought her to a retreat?

A. Yes I did. I thought it would be healthy for her to be in that kind of setting. And I think, in fact, it was—apart from sitting zazen. She did go to some of the talks. It is a healthy environment. People are nice and warm, kind. That part was helpful. I certainly would never force anyone to meditate. It has to come from within.

A very important part of Zen practice is not being judgmental about someone else's practice. Acknowledgment of your behavior is important, but that is not the same as being judgmental. Most important of all is forgiving: forgiving yourself, understanding that you are a human being with all the ups and downs that human beings go through daily, monthly, annually. Metta practice—meditation practice focusing on loving yourself, as well as others—is critical to finding acceptance, both for yourself and others.

Q. That loving-kindness would certainly have to be there for forgiveness as well as self-acceptance.

A. You use a good term—self-acceptance. We are not perfect, whatever that means. With this family member, it was horrible. She stayed in my house. She robbed me blind. I think she may have needed the money for drugs or alcohol—I think she was self-medicating.

I'm still discovering things that are missing. Glaringly, she took most of my collection of fiction and poetry to one of those used book stores and sold them. I miss them. They were my friends, including an autographed copy of Sir Edmund Hillary's *First Ascent to Everest*, which was autographed by his Sherpa, Tenzin Norgay. As books go it was valuable, but it wasn't the monetary value that mattered. It was a gift to me, and it was just very comforting to know it was there. From time to time, I would pick it up. I also miss the poetry collection. Those were two of the things that haunt me. You see, one still has attachments, no matter how long they practice Zen!

Q. In Zen, we are often encouraged to look at how deeply we are attached to something we have no control over. It seems like—Wow!—this is right up in your face, the attachment both to your loved one and her well-being and these very special things that meant so much to you. Poof! They are gone without your having any say in it.

A. Clinging to whatever—to people, to objects—causes unhappiness. It isn't the attachment to the books. It is the missing of the contents. I was missing jewelry as well. The loss of such material thing I can live with.

Q. When you think about attachment and cancer—especially breast cancer—losing a breast, or even a part of a breast, is a very deep attachment to your femininity. Did you struggle with that?

A. I did not. My bosoms have never been a significant part of who I am. It certainly is for some women. I understand that. Before they did radiation, I was on the table with bosoms exposed and they put little tiny navy blue dots on them so that the high-energy

beam would be precisely focused during treatment. The attendant said: “This is a permanent mark. It will never come out. Does that bother you?” It doesn’t. It was interesting to me that she focused in on that, because, obviously, for some women it is a big deal.

Q. There is also the scar tissue from even partial breast removal. In my psychotherapy practice over the years, I’ve heard women who have been struck with breast cancer wonder aloud if they will ever be lovable again as a woman. But that was not an issue for you?

A. No. It wasn’t. Though as I get older it becomes more significant. My body has changed. There is a much more noticeable difference between the left and right breasts. I had two lumpectomies, not a mastectomy, and there is a huge build-up of scar tissue in the left breast, which is disfigured. As my body has changed, I have noticed it more and more. It isn’t worrisome. It doesn’t really bother me per se. It is something that I have noticed. It is annoying. It is not that disruptive.

Q. The first part of your life, you were a high-level broker. Now you have switched to what I perceive to be the diametrically opposite work of a Zen Priest. Which do you like better?

A. They are not that separate. I started meditation practice when I was vice president of a major investment firm. I had two computers on my desk. On one of them I programmed an alert and every hour that computer would flash: “Time to stop and meditate.” I would do that all the way through my work day.

Also, I took great pride in my investment advice and did a superb job for clients. I focused primarily on retirement money and made a vow to myself to always be candid with clients. This was sacred money. We had to build it up so they would not be stone broke when they reached retirement.

Practice is practice. Part of being a Buddhist is being out in the world and carrying your practice with you and reaching out. The practice is always there; how you do that may shift through the years, but

the basic ingredient is being kind and loving to yourself, and helping other people—whether you are collecting recycled goods or whether you are advising people on how to build assets for their old age.

Q. How did others working around you react to your stopping to meditate in the middle of a busy brokerage day?

A. I did not stop as long as five minutes every hour, but it gave me a break. I closed my eyes and breathed deeply. I re-settled and calmed down. Then I would go back at it again with the phones ringing and the ticker tape going and all of that.

Q. The minute the flash went on—did you immediately stop what you were doing?

A. Exactly. If I happened to be talking to a client, I would finish the conversation, then pause, breathe deeply, close my eyes, shut out the world for a few minutes, and then go back at it again. If I was looking at quotes or doing research or doing planning for a client, that came to a halt. Then it would resume.

Q. What would you say to individuals first diagnosed with a life changing condition, whether it is cancer or some other disease? How would you help people to deal with that situation?

A. I would ask them questions: How do you feel about it? What comes up for you? That conversation would help them become aware of their body, aware of what is going on. I am sure the subject of death would come up. These are pretty basic ingredients for a health issue—how is it going to change my life? Then I would probably do some breathing with them and help them to physically understand what that means, the deep inhalations that go right down to your belly button. I don't think the lungs reach that far, but that is the idea. You do the deep, deep inhalation and hold it for a second or two and then slowly release it. Then you repeat that. In our practice we say do it ten times. If thoughts come up, let them go and start all over again. Try it some time. You will be amazed to realize you probably can not get to ten.

Q. Your first impulse was not to give advice, but to ask them what they need, what they are feeling, what are their expectations, then offer breathing as a way to get more in touch with what they are going through.

A. Yes, I find it is more helpful for them to get in touch with themselves. The cardinal rule in that case: this is not about me, it is about them.

Q. How do you help people to get in touch with their bodies? The body is not talking. How does somebody figure out how they can connect with their body beyond what you just described?

A. You can do the basic stuff like scanning your body. When the Buddha gave his very first sermon, he focused on the four foundations of mindfulness, all arising from awareness. That is pretty basic to meditation practice.

One can meditate, understanding that the mind is a monkey mind. It chatters, chatters, chatters. You tell it: “Shut up, go away, I am meditating.” You focus on the body, do a body scan, concentrate your attention on all the parts of your body. Doing this, with practice, will help you really live fully in your body, not just in your head.

Q. What do you do when you hit the painful spots? When you do a body scan and are suddenly aware that there is a burning pain? Or there is a burning fear of the pain to come?

A. You say: “I wish I hadn’t done the damn body scan now that I hurt.” Let’s say you have an injury and you are sitting meditating and it hurts like fury. You acknowledge it: “It hurts. It hurts.” Meditation is not a cure. It is a form of coming to grips with your body. The important thing is that it brings up a lot of stuff. It really works. Try it. You will like it.

Q. Are you opposed to people finding relief through medication?

A. Not at all. However, it is important to ask questions about that medication: Why are you taking it? In our Western culture, there is an overreliance on pills. If I just take a pill, the pain will go away. It may. But that can be a psychological attachment that is detrimental to the stability of a person. It’s an attachment to:



“My doctor says... my nurse says” and “If I pop a pill everything will be all right.” Everything won’t be all right. It is a temporary thing.

Medicine is another tool for coping. But it is not the cure, and it is certainly not healthy to use medication to check out of reality. That would be a misuse of medication. Following Buddhist teachings does not mean opposition to someone managing their illness so that they can function, but to use medication to check out of reality is the antithesis of meditation.

The whole purpose of meditation is to relieve suffering, get rid of the baggage, get rid of the dark stuff that is holding you back. Focusing on the body is very powerful because it brings up a lot of emotional stuff that you need to acknowledge. You don’t have to. You can ignore it and shove it under your pillow. But I believe the important thing is that you do acknowledge it and say, “Ah, this is my body, this is where it hurts,” especially when your body is ill.

Q. As a person who has been ill since childhood, it was very difficult for me to come to grips with accepting what other people would call deformity.

A. Not all illnesses create deformity. With an illness where there is some change in your body, it can threaten your sense of identify: “This is who I am. This is my place in the world.” Suddenly—wait a minute—I am not the person that I thought I was.

Q. That is very true. What would you recommend for a person struggling with this issue?

- A. I would help them find awareness of other aspects of themselves, such as emotions. I am sad. I am happy. I am okay. You don't shove it away. You understand that you are feeling really down and acknowledge it.

The next focus of awareness is the mind. Understand that it is a nonstop computer, with silent programs in the back of it that never stop running. What are the mental subjects outside of your body and your emotions that are disruptive? Becoming aware of who they are, what they are, their bodies and minds helps to anchor the person, provide calmness, clarity, stability.

Q. I appreciate your focus of meditation on the body, because people with chronic illness often check out of their bodies. Meditation can be used as an escape. It can be used as, "I am going to go to my happy place and not be in my body." Why is it important to be in your body?

- A. Because you can learn so much from it. Listen to it. Accept whatever is happening to it—whether it is painful, whether it is deforming, whether it is a challenge to your old identity. The important thing is that you get in there and try to really know your body and listen. That is how you will truly learn about yourself, with body and mind together in the present moment of your life.

NW: Sandy, as always you have been a delight to talk with. Thank you for sharing what I know must be very painful, difficult experiences for you, especially about the family member you love so much. Of course there is always hope that the seeds of peace of mind you shared with her will take root someday. But whether that ever happens, you are truly a courageous woman.



Paula Arai, PhD

Japanese Women and Healing Rituals

Paula Arai received her PhD in Buddhist Studies at Harvard University, under her mentor Masatoshi Nagatomi. She is the author of *Women Living Zen: Japanese Buddhist Nuns* (Oxford University Press, 1999) and is finishing another volume, *Healing Zen: Japanese Buddhist Women's Ritual Lives*. She has spent several years in Japan studying and doing field research. Her focus has been with a community of Japanese Zen Buddhist women (nuns and lay women) and she has maintained close relationships with them for twenty-two years.

Arai has received support for her work through grants and fellowships from the Fulbright Association, Reischauer Institute, Mellon Foundation, Hong Kong University of Science & Technology, Vanderbilt University, Carleton College, and an ATLAS from the Louisiana Board of Regents among other foundations. She taught at several different institutions, and is currently an associate professor in Religious Studies (Buddhism), Women & Gender Studies, and Asian Studies at Louisiana State University.

Q. I understand you are studying and writing about healing rituals used by women in a Zen monastery in Japan?

A. I wrote my first book after having lived with them. My current project builds on that work. Being a field researcher and having a child, it is a little hard to stay in a nunnery. I now study primarily lay women who are affiliated with the Zen nunneries. They consider the nuns at the nunnery to be leaders of the community. It is a community with monastic and lay members. I primarily focus on what the lay women do at home, which is a very different kind of Zen than monastic Zen.

Q. Currently in the West, there is a changing belief that the monastery is not the only place to truly practice Zen. You can do it in your everyday life. It sounds like that is what you are exploring, too. Are you doing your research with women in the United States, Japan or both?

A. My field research is with women in Japan. The rituals are tailored to Japanese culture. One of the things the abbess Shundo Aoyama has written in *Zen Reflections: Seeds of a Female Priest*, a book that has been translated into English, is: "If you think you are too busy to practice, you do not know what practice is."

It is not that you have to get into a lotus posture and sit still. Of course, practice can be that. It can also be cooking soup, cleaning the floors, or driving along the road. It is more about how you approach what you are doing than the content. When I was working with the nuns, I saw many rituals and many things that were not found in Zen philosophical texts or in the secondary research that has followed. Japanese society has changed so much since the beginning of the last century.

In my work, I realized that things these women do in their homes, the resources and the wisdom they have developed over many, many generations, demonstrates a significant shift taking place. Even their daughters are not learning many of the things that these elderly women have learned. To be able to work with them, listen to them, to discover what they are doing has been a privilege. They have rituals and activities that certainly work in their own lives.

One of the keys is being creative and tailoring things to one's own

specific needs—so even if the ritual, aesthetics, and chants are in Japanese, there is no reason someone can't figure out a way to make it meaningful in their own linguistic and cultural context.

Q. There are many ways of suffering. There is physical, emotional, mental, and relationship suffering. In your studies what does healing mean in a Zen and Buddhist context?

- A. Healing means that you stop suffering. In a sense it is no different than the most basic Buddhist goal to be enlightened. Enlightenment means to stop suffering; to actualize wisdom and compassion in your daily life. Healing doesn't mean to cure, although it can involve curing. It is more of how not to be tormented by the situation that you are in.

The word "healing" actually does not translate well into colloquial Japanese. So when I first was trying to understand what women meant by healing, I had to ask: "What do you do when things aren't going well? What helps you?"

I had to find out what help means. I just listened openly. When I started analyzing and interpreting everything that they had been telling me over the last decade, it turned out to be very much in accord with root, basic Buddhist teachings called the Three Poisons (greed, hate, and delusion). Even though I am a Buddhist scholar, I was surprised that when I had formulated the way women express this, healing means to *stop suffering from the delusion that we are suffering*. Feeling alone—one of the worst feelings a person experiences—is a common cause of suffering. Many of the rituals I encountered are about "How do you feel connected?"

The *second part of healing*, in their words, is to *stop desiring things that are not possible*, whether it be that your cancer immediately goes away, or that your child starts acting responsibly, or any of the things that you can't control. It means to stop ramming your head into the wall trying to make it happen. It is beyond your control. Stop wanting those things. Accept that there is a whole lot going on out there and that you do not have all the pieces. You can't always see clearly what may be the best thing.

The idea of these rituals is to try and relax in the situation where you are not able to get the things that you want. Many of the rituals help you learn how to breathe and to be in the situation without



wanting it to be different than it is.

The *third aspect* is to *stop being angry about things that you do not like*. This is a cousin to the second principle to stop desiring things that are not possible. Being upset and frustrated and even turning to bitterness and resentment is not healing. If you can stop being angry, you can actually use that power and the energy of that anger to transform it into positive energy and to integrate these thoughts and feelings.

It requires one to stop being judgmental and to stop saying things such as: “Oh, I like this. I do not like this. This is good. This is bad.” You have to have a narrower perspective to assess that something is good or bad. If you have a really large perspective, then things do not fall along those lines of good, bad, like, and don’t like. The women I observed have several rituals that help them expand their perspective. The rituals help them feel connected. They help you find breathing room when you are dealing with situations that you want to be different. They help you expand your perspective enough so that you do not get all tied up and stuck thinking, “This is good. This is bad.”

The most striking thing not necessarily shared across all Buddhist traditions, but found in the particular Soto Zen tradition of Buddhism, was that *healing only happens in the present moment*.

That took my breath away, once I realized what they were talking about. It is not that you do rituals in order to eventually heal at some point in the future. You can experience healing in any given moment.

Ten minutes later, you could be racked with pain and your mind can

torture yourself with wanting it to go away, wanting something that isn't there, not wanting something that is there.

Then again, you can do some rituals that help you breathe in a way that helps it not be so bad anymore. You get a different relationship to your circumstances—whether that is a different relationship to the pain or a different relationship to the people around you.

Healing is something of the present moment. It can come and go. Many people suffer because we have imagination and we can imagine what it would be like without our illness. We have memory and we can remember what it was like without our illness or pain. Living in that past or that present or that imagination of the future is extremely painful; you are certainly right now to ease your suffering.

Q. Please tell us about the rituals you have observed in Japan and how they help these issues.

A. The most striking aspect to me is what I have termed “domestic Zen.” My first book was all about monastic Zen, with which most people are familiar. The characteristics and qualities and aims of this kind of Zen are different enough that I want to give them a different designation.

Domestic Zen sounds almost like an oxymoron. The domestic sphere is messy and emotional. People are trying to work things out—not necessarily in a clean, calm, serene manner, which is the hallmark and ideal of a Zen monastery. The popularized version of Zen is that it is all calm and balanced. That is not necessarily what happens even in a monastery, but it is more unlikely in the domestic sphere. What the women described to me was like an anchor or harbor of their way of practicing and living Zen. This anchor is called a *butsudan* or home Buddhist altar.

There is a space in the home that people can turn to in order to make offerings or to chant or to pray. In most Japanese Buddhist altars, deceased family members are honored. The understanding is when a family member has passed away, their death is a way to enlightenment. The deceased is understood to be a Buddha. The way this ritual and belief works in the lives of these women is that they continue the relationship with the deceased, but are also transformed. The deceased is recognized as a Buddha. All the complications, intricacies, the past bad memories, fade away. You can turn to your “personal Buddha” who

knows everything about you and can listen to you, can be there for you. That person is seen to be the Buddha in the home altar.

You can have more than one Buddha in an altar, of course. There may be more than one deceased family member. People will also usually have a Shakyamuni Buddha or Amida Buddha. The intimate relationship is usually with the particular person who has passed away—a person you may go talk with who listens to you patiently and deeply, for this person is now your own personal Buddha. It is a very powerful healing when you feel you are understood and not judged. People go to their home altar for these reasons.

Some people have an entire room dedicated to it. Other people dedicate a little corner on the top of their bureau and have a picture, incense, flowers, or even a tiny cup of tea. First of all, it is important to have a place where you can go to be understood and feel safe. That is a very big part of domestic Zen. Also, to make the offerings is a chance for you to get beyond yourself a little bit. A lot of suffering comes from being too focused on yourself in a very narrow way. Everything gets distorted to a pinpoint.

It is hard to keep your balance when the wind starts blowing if you are only balanced on a pinpoint. Even just giving a cup of tea to someone else can give you the opportunity to make a connection. Then there are two pinpoints and you are better balanced.

The offerings remind you to put your “self”, or in Western terms, your “ego” aside, and behave with generosity towards others without thought of YOUR want.

The chanting often done in rituals is quite literally your breath. If you are chanting and you are doing a whole lot of exhaling as you are chanting, it slows everything down. All the stress that can build up may dissipate when you are chanting. The whole body gets a chance to relax and breathe more deeply. It gives you that breathing space, quite literally.

The prayers you speak to your personal Buddha about the problems you have are a chance for you to pull your own energy together, to make connections to something larger than yourself. Holding your hands together in prayer (*gassho* in Japanese) completes the electrical circuit in the body. When your hands are separated the energy scatters. When you are sitting in prayer with your hands together, your energy

has the chance to collect and gather and get stronger because it is not getting dissipated. It has a chance to build up in this very safe place at the home altar. Those are daily ritualized activities that the women do that help them keep balance.

They are steadier with just those activities. That is the mainstay of domestic Zen ritual practices.

Most of these women do not meditate in ways often practiced in Zen in the United States, where even lay people will do a lot of zazen or seated meditation practice. That certainly can be very helpful, but that is not very common in domestic Zen in Japan.

Q. They find chanting and breathing better than sitting meditating for becoming calm and clear and centered. It is much more an active process?

A. Right. They have all the things going on around the house—it is not a monastery. One woman said she always does her chanting in the morning, specifically when everybody is leaving to go to school or work. The altar room is right by the front door, where everyone leaves. Her scripture chanting is punctuated with: “Don’t forget your lunch. I am not going to be home. Take your key.”

She does that specifically so that everyone else in the family knows there is this harbor they can go to. She doesn’t think it is effective to just tell them you can do this. She shows them by doing it. It creates an ethos in the home and in the human relations. I think of these ritualized actions as brakes that keep you from going too quickly back to that pinpointed self. These are things that can slow you down and keep you connected and aware of how you are interconnected, which is the prime quality in these women’s healing paradigm.

The key is to experience interrelatedness. We can all think with our heads: “Oh, yes, trees become paper. I am holding this paper. The trees grew because of the rain.”

We can all think about how we are interrelated, but that won’t heal you. We have to feel it. It has to be an experience that you are interconnected. These rituals that I have described to you are the basic ones for feeling interconnected.

Q. You mentioned putting a picture of the deceased on the altar. Is that connected to Japanese ancestor worship?

A. Japan got it from the Chinese. Ancestral rituals are done through Buddhism in Japan. These distinctions are academic categories and distinctions that in the real world are never so neat, though it did come out of China. There is no other Buddhist culture that thinks of the deceased as a Buddha. That is distinctive to the Japanese.

Q. In the United States, chanting may not be what people are familiar with, although prayer might be. I have found a lot of similarities between the chanting I do during Zen practice and the praying I did as a child. There is that kind of comfort. Is there a way you could advise American women who are suffering and need that healing space?

A. One of the practices that the women do is mantra practice. They use a couple of different phrases during times of great stress—for example, when running to the doctor if your child has broken his arm, or your child has spiked a fever during the middle of the night, or you are terrified while waiting for a medical diagnosis to come to you the following day and you cannot sleep.

One of the chants or mantras is *Namu Kannon Riki*, which means, “praise to the power of the bodhisattva of compassion.” This is a mouthful in English. It is useful to find some phrase that would be meaningful to yourself. It can be very powerful to come up with something yourself. It hits the spot, because you know the exact point.

There is a distinct power that comes when a community has decided—even if the community is you and your best friend—to come up with a phrase. The key with this type of mantra is that it helps you feel connected with something bigger than yourself. That business of feeling alone is tenacious. You have to keep reminding yourself you really aren’t alone. To have a mantra you have chosen ahead of time is to connect you with something larger. It is meaningful to you. You have a world view that there is some compassionate power that is there for you. You can then quite simply chant it under your breath or even silently, if you do not want anyone else to know.

If you are sitting in the emergency room, you can be doing your

chant. When it is so intense, it can really help you think straight. It is about trying to find balance in that situation. To have something that makes you feel connected, not something that you just cerebrally know, but you are familiar with it enough that it feels like: “Yes, I am connected.”

Q. It sounds as if a chosen mantra says: “I am not alone. There is comfort and compassion right here for me if I let myself feel it.”

A. Yes, right now. That is the point. In domestic Zen, it is all about what is pragmatic, direct, and immediate in meeting your needs. Different women do different things. They create their own rituals and mantras or prayers.

Japan is a big gift-giving culture. People want to give gifts that are practical. Nobody can receive a bunch of stuff that they do not need given the small homes typical in Japan. They give soap or detergent or things that you can use up and that you are assured everyone will use.

One monastery Abbess gave gifts of cleaning cloths to women. Originally she gave a cloth to a woman who had cancer. The Abbess had a Buddhist artist paint calligraphy on the cleaning cloth. It was very lovely. She could have used it for a cleaning cloth, but she thought of it as something very special from the Abbess and so treated it as the special gift that it was. When the medical doctors said that they could do nothing more for her she took that cleaning cloth and laid it on her pillow. Her husband had a specially gifted cloth as well and he put it on his pillow. That simple act helped her feel embraced by compassion. She felt okay, not that she was going to be cured, but that she was okay. It is now over fourteen years ago and the doctors have not been able to detect any signs of the original cancer.

She just made up her own healing ritual. Now it is a big thing in this community to get one of these cleaning cloths. That was never the intention of the Abbess. She simply gave the ill woman a gift from her heart, a gift that was useful as well.

I am telling you this because there aren't any rules. If something works for you, it works. It has to be meaningful to you. Since we are at this point when things are transferring across cultures, there is more forethought, a deliberate decision-making dimension that you would not find in a culture that grew up with the rituals. Find something

that speaks to your own heart and your own situation, something that makes you viscerally feel connected beyond yourself, something that makes you feel safe. Even in your most vulnerable, desperate situation, you know there is some bigger power that can hold you, comfort you.

In general, the various ritual practices of domestic Zen are simple, not elaborate. They're something you can do when running to the doctors or when you are so distraught you cannot put two sentences together. More importantly, there are no fixed rules for the healing rituals. They can be created individually, so each woman can apply the prayers to her specific need.

Q. What would you say is the most important significance behind these domestic healing rituals?

A. They mean that the universe is here supporting you, down to the basics; that we are all connected in so many ways to each other and to all things. Our bodies have carbon. The stars have carbon. We are part of something bigger.

There is a Japanese verb, *tsukiau*, which means to have friendly interactions with somebody or something on an active basis, not a friend you only see every ten years, but someone you may have coffee with as often as you can.

This verb is used not only when referring to relationships with people but with circumstances as well. One may ask, "How are you going to *tsukiau*?" or have an *interactive, friendly relationship* with your situation? If it is with your cancer or with your chronic hip pain, how do you become friends with it? If everything is interrelated, there can't be enemies. It is not about attacking or wanting to get rid of something. Is it about how you make friends with it. If you are trying to make friends and realize—okay, my pain is not so bad. If I don't feel like walking two miles a day, I don't. On days it hurts, I will just walk one mile, or maybe just one block, and make friends with the pain. You are together with it. It is not something outside that you need to fight.

The key is: How do you interact? How friendly are you with whatever the situation is? It takes a lot of energy to resist. By accepting it, it doesn't mean you throw in the towel and say, "OK, you win." It is not like that.

These concepts of “like” versus “do not like,” “good” versus “bad,” *are just concepts*. They have so much power to shape how we experience things. One of the keys to this healing paradigm is to **change your perspective**. If you are suffering, that means that your perspective is too narrow, too small. The more you expand it, the less alone you feel.

Another metaphor for this experience is, say you are out on a raft and you hit some whitewater. It is easy for your lone little raft to topple over. But if there are a bunch of people on rafts and you all tie them together, then you have a bigger network that can ride the waves, so you do not tumble over.

Whatever will work for you is that place where you have the sense that you are now tied together with whatever else—other people, nature, the cosmos—that will help you feel the connection to something broader. The bigger it gets, the less suffering. There will be more stability. It is not so difficult to be balanced.

The narrower the perspective, the more difficult it is to find your balance and maintain it through all the vicissitudes of what goes on in life.

Q. To take this perspective another way, without this interconnectedness, is it like trying to balance on one foot? You are not going to be able to do that for too long.

A. Right, it is almost like you are actually connected to all these other things and you do not realize it. It is in your head that you are standing on one foot and alone, but in reality you actually already are connected.

The important questions are:

How do you access that?

How do you feel that down to your marrow?

How do you feel that you are connected?

Another phenomenon in Japan is that before people go into surgery someone might hand the patient a rock that says *daijobu*, which in Japanese means, “It is okay.” People go into surgery holding these rocks saying, “It is okay.” That is not to say you are absolutely going to get through this with flying colors.

Q. Is it a reminder that somebody is thinking of you, caring for you, waiting for you? That the giving of a gift means, “Here is a piece of me. Hold onto it. I am with you.”

A. And a piece of *the earth* is with you. If you can feel rocks that way, then it will have more power to help you find the balance and not suffer. Whatever works. It may be something in the family that has that power to make you immediately and viscerally feel that kind of connection. Anybody in any culture could find something that is helpful.

Q. You have given an example of a woman’s cancer somehow healing through, perhaps, the generosity and feeling held by the world. How do women with chronic, unremitting pain approach these rituals?

A. An insight that came to me when listening to the women is that each one is like a cell in the universe. When they are feeling really bad, they try and think of themselves as being five billion years old. You can’t fall off the universe. There is nowhere to go. As soon as I realized I couldn’t fall off, I realized that must mean I belong. You belong and are integrally part of something when you can’t even get off of it. When I feel alone and sorry for myself, I now know I cannot go anywhere else. You cannot leave the universe.

The Japanese women say that to heal is to wake up to realizing you are already healed. You awaken. You are healed. The universe is already supporting you. Do whatever it takes for you to change your perspective so that you see or feel those things clearly.

When the women give offerings or perform a whole host of rituals done in temples for ancestor commemoration, they are not doing them in order to heal. They are just doing them to commemorate their ancestors. The experience of healing is really a by-product.

In a sense the deepest healing comes from knowing that you are completely interconnected and you are already healed. To aim at the core belief —“Okay, I am going to feel I am completely and intricately connected to everything and that will help me heal”—is a target so big that as soon as you conceptualize it, it becomes smaller, accessible and manageable. This sense of connection has to be a bodily experience.

Just lighting a candle, lighting incense, putting your hands together, bowing to the sunset all connect us with the physical world.

Q. So you are saying there is a part of the rituals about which you need not to be so cerebral?

A. You just have to use your body. You could call all those things meditations. I don't. I call them ritualized activities and see meditation as a kind of ritualized behavior and not the other way around.

Q. In the West there is some pressure to meditate "the right way." People feel bad that they are not doing it or not doing it well enough. A lot of psychological baggage can come with talking about meditation. Would you please speak to that issue?

A. It is really a different cultural context, but in the Japanese context, people do not think in those terms. They have these smaller, non-cumbersome activities throughout the day as a way of seeing and feeling. This approach will take a long time to make more headway in American culture. But I want to take the pressure off people who feel as though "I am not a good mediator and therefore I am not going to be able to benefit from this."

One of the studies that I am beginning with a neuroscientist at the Salk Institute, Sascha du Lac, is about bowing. There are now increasing studies on the meditating brain. Those are wonderful, but there are no studies about the effects of bowing.

Because of the feelings of inadequacy that many feel... the pressure to do it right, the feeling of not doing it well enough... the vast majority have not done rituals.

When I think like a scientist, I think okay, we are going to try and isolate some activity. What about bowing? I phoned Sascha and suggested that we look at it. When you bow you are like an animal in very vulnerable position. You bow down and can't see what is going on around you. In order to do it voluntarily, you have to feel like you are in a safe place. Bowing is the opposite of the fight-or-flight reaction of chemical and electrical processes that go on in the body when one is afraid.

One of the key parts of the healing paradigm for the Japanese women is gratitude. That is a shortcut to healing. If you are bowing

down in gratitude, your body knows, “Okay, I am in a vulnerable position, but it is okay to be like this.” Then you are setting off these different responses in the body. When you are cultivating or experiencing that sense of gratitude, you cannot complain. When you are grateful, you cannot complain. When you are grateful, anger does not come.

Q. It does seem difficult to carry both anger and gratitude at the same time. Have you found that in your research?

A. I would advocate bowing (although the research is not done yet), but Buddhists have been bowing for a couple thousand years. Most of them have not been meditating all these years. There must be something to it, otherwise people would not keep doing it.

Incorporating a kind of bowing with a sense of gratitude does not have to involve any words. You just physically have to put your hands together and bow your head, whether you are standing or sitting. If you can't get your hands together, cross your legs. Have two sides of your body touching—two hands, two feet, somehow connecting. The lotus posture is essentially all about getting both sides of the body connected. Yet it does not have to be complex connection. It can be as simple as touching side to side.

I am not against meditation whatsoever, but seeing the Buddhist cultures in different contexts and different historical time periods, this American stress on meditation is a distinct development in Buddhist history. It seems to encourage lay people to think they need to meditate in order to be Buddhist or in order to benefit from Buddhist practice.

Q. You are offering a whole different array of practices that appear to achieve the same result as what we seek in a meditation: to be completely in the present moment, calm your thoughts, clear your head. Are you saying that one doesn't just have to sit still?

A. Most people don't have time to meditate. People in Japan don't usually have dryers. When the sun comes out, they say: “Good, I can get the sheets dry.” They have that sense, “Thank you sun. I am so happy to see you today.”

By feeling gratitude for those little things that have to be done every day, you can see how you are already supported by the universe, see

how you are already connected. When you are cutting carrots for a soup, thank the carrots as you are cutting them. These things that are interwoven through daily, necessary activities allow—as they say in Japanese—a certain orientation toward living. You always have a choice. You can heal in the moment. Knowing that it is possible is very powerful.

Even if bowing is hard, try to get your fingertips touching and just lie there. Lying there, say your mantra—something that makes you feel connected to something bigger, something that helps you breathe into the moment and not begin that cycle of wishing things were different, of getting angry at the way things are, of feeling alone. Anything to put the brakes on those three things will make a difference. If you cannot find the words, you can just breathe with a sense of “I am connected. I am okay.”

Q. Thank you so much Paula, for sharing your research and teachings with us. Your understanding of these issues provides a better understanding for us all. How can people get in touch with you and find out more about your books?

A. My first book, *Women Living Zen: Japanese Soto Buddhist Nuns*, I hope to soon have out in paperback; it's available in hardback at Amazon.com and at some book stores. The book I am working on now, with the University of Hawaii Press, is called *Healing Zen: Japanese Buddhist Women's Ritual Lives*, I hope to have published in spring of this year. I also have an article that covers the personal Buddha rituals and a chapter on other rituals in an edited volume entitled, *Zen Rituals* (edited by Steven Heine).

The Japanese Buddhist lay women in Japan entrusted me with their wisdom and their stories, their pain, their vulnerabilities, because if they could say anything that could help anyone else, they wanted to do it. I am their messenger. I am honored that they would trust me. They are the ones who have learned this the hard way. Many of them thought they would pass on before they would be able to share it.

NW: We are very lucky to have you there, observing and listening and recording what may have been lost amid all the focus on traditional meditation. Thank you for work that is both scholarly and compassionate.





Karen Cook

Living With Parkinson's

Karen Cook taught creative writing, literature, and English composition at a small college in the San Bernardino Mountains before moving to Bellingham, Washington, with her husband in 2003. Karen was first diagnosed with Parkinson's Disease in her 40s, after spending many years refinishing furniture as a hobby. She devotes most of her time to hand-making heavily embroidered art quilts, collages, and watercolors. She has three grown children and two grandchildren.

Q. How was Parkinson's first identified as a neurological condition?

A. One of the clues for Dr. Parkinson was a study of a group of men who had symptoms so similar that he was able to put them under one syndrome. They were finishers or refinishers of furniture who worked in closed rooms with extremely strong solvents.

He saw a very high incidence of tremors and other symptoms in these men, a cluster of problems they all shared. This was the rationale for him to identify a new syndrome.

For decades my hobby and obsession was refinishing furniture. Once my symptoms appeared, my son went online and discovered the information regarding Dr. Parkinson's study of the refinishers and the solvents, not known at that time to cause neurological damage.

I had been refurbishing furniture for forty years in closed rooms using similar compounds, which did, in fact, have warnings on their labels advising people to work with them only in well-ventilated places. I never had any symptoms then, but I am convinced that this is a strong possible source of my symptoms now. There is no history of neurological disease in my family at all.

Q. Do you still refinish furniture now?

A. Due to my developing symptoms, I have given that up. I have become an artist instead. I do not have the physical strength to refinish furniture anymore; but I do not beat myself up thinking I did this to myself. We all did things that were harmful to our bodies without realizing it or being warned of the dangers. We ate hot dogs with nitrites and other foods now taken off the market as they are toxic.

Q. What are your symptoms?

A. I have what is called tremor-dominant Parkinson's, even though you would never know. The medications that I take are very low dosage: Carbidopa/levodopa and Mirapex, and they mask the symptoms almost completely, except when I am very agitated or upset about something. Then they come out very forcefully. Typically, people do not see my tremor. I have no rigidity. I do not freeze. I do not have any of the classic motor symptoms. I have what I call "head symptoms," which are much worse in my estimation.

They involve very frightening symptoms that are hard to describe. For example, I get a feeling of extreme pressure inside my head, but without pain, as though the contents of my head are too big for my skull.

Extreme anxiety and tension come out of nowhere, even when I am doing something that I love. They feel rather like panic attacks must feel, except that they are not related to anything that I am aware of. I do not hallucinate, but the anxiety is extremely frightening; so much

so that I revisited the doctor who diagnosed me, Chadwick Christine at UCSF Medical School, a leading researcher in the non-motor symptoms of Parkinson's.

We talked about it for several hours. He is familiar with all of these symptoms, which are hard to treat. It is difficult to describe them and it is very difficult to treat them without putting people on heavy psychotropic drugs.

Q. How do the medications interact (or not) with your meditation? Have you found meditation to be a useful adjunct to the medicines?

A. The meditation nourishes something else. It nourishes a sense of hope. It temporarily creates a sense of calm and peace. Sometimes this effect lasts for many hours. But I find that I can't get that by meditating alone. It has to be in a group for some reason. I am obviously picking up energy from the other people, who are all Buddhists, although I do not describe myself as a Buddhist.

It is a wonderful feeling. No matter how bad I feel when I go in there, no matter how agitated or discouraged, I always feel one hundred percent better when I emerge from one of these sessions. It is remarkable.

I have found many people who meditate do not label themselves as Buddhists. But most agree meditating in a group enriches their practice and often leads to sharing that feeling with others. I have never encountered a meditation group like this before. My work with the AIDS assistance movement in the early 1980s was the only other time when I felt this tremendous outpouring of kindness and love.

There is nothing sentimental about it. It is not touchy-feely. It is a very deep thing, silent, but unmistakable. When I go to meetings with the sangha, sometimes there are little ceremonies or parties. The feeling is there, too. I do not feel this in my own church at all. I only get it in this meditation group.

Q. People may be apprehensive about exploring meditation when unfamiliar terms like sangha, Buddha, and Zen are used. Did you ever find this a barrier to going to a meditation group? Or did you ever feel pressure to join or make a long-term commitment to participate?

A. No. I joined because I like the community so much. I wanted to make a contribution. I am not reliable physically. I have good days and bad days. I cannot be relied on to do volunteer projects on a regular basis. But I can make my contribution by joining as a supporting member.

I never felt any kind of barrier at all. If I am still considered Catholic, I am a very, very, very left-wing Catholic. There is nothing farther away from Buddhism than Catholicism, which is a very rigid religion in many ways. People in the Buddhist community are so welcoming and so interested and so engaged that I felt embraced from the first day I went.

There is a little ceremony after the meditation in which we read the Metta Sutta , which is a beautiful statement of Zen.

The first time I read it aloud, I realized that there is nothing in this sutra that I do not agree with completely, unlike certain prayers in my own church. I can say I embrace this philosophy of loving kindness completely. It is a perfect reflection of my own philosophy of life. It is timeless and beautiful, based on kindness and sharing and mindfulness.

I love participating in that ceremony. It is like a maraschino cherry on a wonderful ice cream sundae, because it tops it off so perfectly. I have sent copies of the Metta Sutra to all of my most bigoted friends. It is so gentle and so unobtrusive, but it has many important lessons presented in a beautiful way.

One of the things that affects me deeply is the place where I meditate. The Red Cedar Dharma Hall in Bellingham, Washington, is a place that has an unmistakable atmosphere. The minute you walk into that space you exhale all your anxiety and all your hang-ups. It is a place of great peace and welcoming, even if you are not in that condition yourself at the time. It encourages those feelings. There's a feeling of warmth that is generated by the people who created the space. They worked very hard to create it. The spirit that lay behind it, the feeling they were after, is tangible. It really makes it possible to enter into meditation very easily and wholeheartedly.

Some of them, the other sects, are more rigorous than others. Zen is the one that feels most lacking in ritual, less rigid to me. Although I suppose it depends on what you were expecting. For those of us who are ex-Catholics, there can be a familiar appeal to the forms of Zen.

In the group I attend there is a young priest who is a follower, as much a follower as a leader. There is no real hierarchy in this group although there are priests and other figures: lay teachers, senior students. It is not a rigid hierarchy. You don't bow down to these people. When we bow, we are bowing to the Buddha nature, the true goodness, in ourselves.

This young priest is so down-to-earth. He is so modest. He presents a really good example of what the goal is: selflessness. It is not self-sacrificing and doesn't involve that kind of self-abasement that they teach you in other religions. It is learning how to put aside and be much freer in the way you think and feel and relate to other people and to the world. It is wonderful. It is very freeing.

This is on the basis of once a week for me. Heavens know what it would be like if I went three times a week. I am thinking of expanding my practice. I really love it. It has made such a difference to me that I am thinking—why not make triple the difference and go a couple of extra times each week?

Q. Health-wise, how would that work? How might sitting very still for periods of time impact your Parkinson's?

A. It depends on how I am feeling. If I woke up feeling really bad this morning, or if I had one of my head episodes where I was having intense physical and mental symptoms, I could not go to the meditation hall. I could not get there by myself. My husband would have to drive me.

There are times when I feel really unable to go. Also, I have bronchitis fairly often. I worry sometimes that my coughing will disrupt others' meditation. I don't go if there is any danger of contagion. I also carry cough drops at all times so that I can pop them into my mouth if I feel a tickle in my throat. It is really important to me not to disrupt the meetings for other people.

Q. That is kind of you to consider your neighbors. Sometimes coughing, sneezing, and snoring happen. These things can actually help people with their practice: accepting the reality of being human.

A. I have this really embarrassing thing, because of the combination of meds that I take, of nodding off at odd times. Because I

can keel over from one side to another at random moments, I sit in an arm chair that gives me support on both sides. That is my strategy for not falling on some poor soul who is deep in a meditation. This particular sangha is so wonderful and light-hearted about that kind of thing that I never feel that I am a burden or a liability. Everyone just makes you feel quite the opposite, which is really wonderful.

Q. Did you discover meditation before the symptoms of Parkinson's were present or after they emerged?

A. I had not meditated for many years. I used to be a twice-a-day meditator. I went to the American Meditation Society because I did not like the sort of ceremonial, quasi-religious aspects of transcendental meditation, the more popular form of meditation in those early years. We had some good instruction. My husband and I used to meditate half an hour, twice a day. Then, for some reason we got away from the regularity of it and had not done it for many years.

After I got Parkinson's, I felt that I had to do something besides taking medications and exercising. I had to do something for my sense of spirituality. Another thing that I really enjoy is that the Bellingham group is very mixed in terms of age. Sometimes we get this wonderful kid who is only eleven or twelve. How many eleven- or twelve-year-old active boys with lots of energy can do a meditation sit? Depending on the composition of the group each day, you get a very different feel of energy. It is wonderful. It is always surprising. It is always different.

Q. You mentioned you do a number of things to help the symptoms of Parkinson's. You take medications. You exercise. You meditate. Where is meditation in the order of coping activities?

A. There are three things I do besides taking my medications.

Number one is art.

Number two is exercise.

Number three is meditation.

The art is number one because it is my passion and because I discovered that just by doing it the symptoms go away.

Q. Were you an artist before the onset of Parkinson's?

A. I was, but I was teaching college English. I did not have a chance to do very much art. When I retired my husband and I moved to Bellingham. I threw myself into art.

Lo and behold I discovered that there have been several major studies that have determined that doing graphic art of any kind dramatically relieves the symptoms of Parkinson's. I did not know that when I returned to my art. It was not my reason for doing it. I do it because I love it so much. But it works! It also works for other people in my Parkinson's support group. It is quite amazing. I know, too, that exercise is critical as well.

Q. Is it difficult for your body to exercise?

A. Swimming is my main exercise because I have a bum knee with very bad arthritis and I can't hike anymore. I swim. I love to be in the water. I also do an hour of yoga and Pilates between 4 and 5 in the morning six days a week. I go to the gym three times a week to do what work outs I can for that day. I am committed to strengthening my body whenever I am able.

For people with Parkinson's, the more exercise you can do the better. It is critical. It helps with balance and I find that I do not have any balance problems when I maintain my exercise routine.

Q. Do you have any advice for others struggling with such physical limitations?

A. I recommend that each individual finds his or her own limits, and exercises within those limitations. My main small motor endeavor is to make neo-Amish quilts that are in the spirit of the Amish without copying their designs. I am experimenting recently with Rally quilting, which is a Pakistani tribal-type of quilting involving a lot of embroidery.

The repetitive motor activity of hand quilting is immensely helpful to me physically and emotionally. It is a form of meditation for me. I will do it for hours. When I do this I do not listen to music or distract myself in any other way. It is very much like a rhythmic movement meditation for me.

Another small motor meditation I try to do is with my grand-

daughter, who insists on doing watercolors with me. She is a five-year-old and quite persistent. I have no choice. She is my art guru.

Q. If you were talking with someone who was just diagnosed with the symptoms of Parkinson's, what would you say to them?

A. I would say—don't regard Parkinson's as your enemy, as something that is bent on destroying you or wrecking your life. Try to look at it as an opportunity for learning. From the start my approach to this illness has been to ask: "What can you teach me about myself?"

I have learned so much about myself with this disease. I thought I knew everything about myself. I have had Freudian analysis and later Jungian analysis. I thought, "Well that should cover everything." Baloney!

From having Parkinson's I have learned some things about myself, like how impatient I really am and how irascible I can be.

With a chronic illness you have a rare opportunity to stop wasting time, because you do not know how your disease is going to progress. Meditation helps with this—helps me stay focused on what I am doing or want to do NOW—not sometime in the future, when I cannot know (nor can anyone really) how much future is out there for me.

Q. How long have you been practicing since you returned to meditating?

A. I have been practicing for a year and a half.

Q. Does your husband continue to sit meditation as you both did early on when you first met with the American Meditation Society?

A. No, he no longer likes to meditate, but he is very supportive of my practice. He will sit with me at times when I have head spells or anxiety attacks. He doesn't try to fix it. He just sits quietly with me and this is very helpful, very loving.

Q. What would you recommend for people with Parkinson's or other chronic illness?

A. Be merciful to yourself. That is very, very important.

There are times when I feel very discouraged, very clumsy. One of my head symptoms is that I can't take in certain kinds of information anymore. It is very hard for me to take in instructions, how to set up a TV—that kind of technical stuff. I just can't do it anymore. I can do certain other things—artistic things—that I couldn't do before. It balanced out. Forgive yourself for diminished capacity.

That is absolutely important. Otherwise, you can get so discouraged.

Q. You have talked about how meditation helps you. What would you say to motivate a person to consider meditation? Why should they bother taking the next step?

A. It is a very specific kind of thing you are doing for yourself that is very different from any of your other day-to-day activities. It is stepping outside of that quotidian world, which is very driven and hectic for most of us, and stepping into something that is quite timeless.

Q. Do the head symptoms you speak of ever prevent that process?

A. No, but my constant thoughts and feelings can interfere. I have heard it called “Monkey Mind,” thoughts leaping from tree to tree. That is a very common metaphor in Zen literature.

Q. How important is family support? Often, the family needs to do a little extra because of the illness. What has this been like for your family and how important is that support?

A. I have three grown kids I feel very close to, but they don't want anything to do with this disease. It scares the heck out them.

Every now and then I update them. I send them a little letter saying this or that is happening. They never respond. It just threatens them so much. They see what is happening to me. Unfortunately they don't always see the way I cope with it or don't cope with it from moment to moment. Denial appears to be their coping response; and that is too bad as they miss all the day to day moments we could share.

My husband went from being very impatient with me—“You are not trying hard enough”—to being the most wonderful caregiver. My only criticism of him is that sometimes he tends to be a little over solicitous. I am not a cripple. I am not completely disabled. I want to

just take it from whatever level I am at now. Please don't anticipate that I am going to be worse. In general, he has been an angel. He has been incredibly gentle, sensitive, and aware of anticipating my needs. There is no sense of him begrudging anything. His heart is open to me in this situation.

As I mentioned earlier, when I am feeling very bad, he sits with me. He doesn't do anything. He doesn't try and make it better. He is just there, which makes a huge difference to me.

Q. You mentioned that your children seem to want to avoid the entire issue of you illness. Why do you think that is?

A. I think they are terrified. I understand that. My grandchildren are much more comfortable about it. They ask me questions such as: "Nana, why are you so slow?" "Why is your hand shaking?"

Once in a while I will shake if I have neglected to take my medication for a while. I tell them why and give them whatever information they want and no more. It is great. The whole issue of illness seems so natural with them. Children are not afraid of the facts. I really love that, when a child will freely, comfortably ask me, "What is wrong with your hands?"

I have a niece who is a very empathic girl. She is eight years old. She said, "Karen, why is your hand shaking?" I told her. She took my hand between her two hands and she said, "I am going to heal you."

I think that fear is the great enemy. I had not been afraid at all until I went to a memorial for my husband's best friend. I gave a little speech about his deceased friend's wife. No one else had mentioned her. My whole body started shaking in an uncontrollable way. It was terrifying.

I did manage to finish saying what I was planning on saying. That scared me. Nothing like that had ever happened before. I realized that this is an unpredictable thing. That was the first time I had ever been afraid. Whatever you need to do to deal with the fear, you do it. I strongly suggest reading Steven Levine. His books are matchless in working with such fears. I do think that fear is the hardest thing we must contend with when living daily with an unpredictable illness.

Another useful book is called *Full Catastrophe Living*, by Jon Kabat-Zinn. He recommends that you just embrace whatever comes and take it in instead of pushing it away, which is truly the core of Zen meditation practice. His book is a wonderful starting place for fighting

whatever your reality is versus accepting and learning from it. He also wrote *Wherever You Go, There You Are*. He has great titles.

I see people in my group who have had Parkinson's for twenty-two years and sometimes even longer. It is fascinating to see how each person deals with it. Some people are clenched against Parkinson's. They resent it. They are bitter and angry.

Other people become more generous. One man had a horrible whole body tremor until he had deep-brain stimulation surgery. Even before he had the surgery, he'd come to a meeting with big bags full of material to hand out to people. He has such a generous spirit that even severe suffering of such disabling physical symptoms didn't stop him from giving to other people. That was exemplary.

Q. Is it difficult to be in a support group with bitter people?

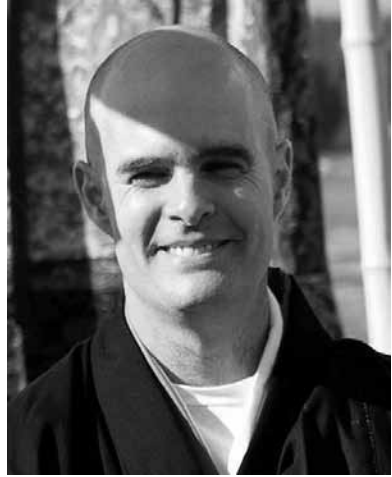
A. I facilitated several AIDS groups for seven years. I encountered everything in those groups. There were men who were terribly bitter and angry and hostile. I learned to truly accept and love them just as they were. That gave me a tremendous leg up in dealing with Parkinson's.

I have no idea how I would have responded without having learned from their experiences. I suspect I would have been very frightened, angry and hostile. The AIDS experience gave me so many tools for understanding my own and other people's reactions to illness and suffering and just accepting people wherever they happen to be.

NW: Thank you Karen, for sharing your intimate experiences with pain and physical limitations, and for explaining how meditation has helped you. You are a wonderful model of one who just accepts what IS, even your own suffering. I look forward to seeing you in the Dharma Hall when your health allows.



Tim Burnett sweeping a temple court yard of Rinso-In, one of the more important advanced Soto Zen training temples, presided over by Hoitsu Suzuki, the son of the founder of Western Soto Zen, Shunryu Suzuki Roshi. Suzuki left Japan for San Francisco in 1959, believing against the protests of his Japanese teachers that Westerners could learn and seriously study the teachings of the Buddha.



Tim Burnett

Zen and the Art of Caring for One's Family

Tim Burnett is a Zen priest who began his study of Zen when he was still in his teens. He has devoted the past twenty years to developing and sustaining the Soto Zen sangha in Bellingham, Washington. Tim will receive Dharma Transmission from his teacher, Zoketsu Norman Fischer in July of 2011. Has spent the last two years studying Jon Kabot-Zinn's program of "Mindfulness Based Stress Reduction," and is authorized to both treat clients and teach the concepts of the program. Along with these significant achievements, Tim is also a computer expert and develops programming for many different organizations. He is married to Janet Martinson and helps raise their young son, Walker.

Q. Tim, would you please say a bit about yourself and family?

A. I have known my wife, Janet, since I was a teenager. About three or four years ago, she came down with an undiagnosed, chronic

fatigue syndrome, which causes her to be unpredictably very tired. Since then, she has been unable to work. Her condition has been challenging for us.

One of the biggest challenges in caring for someone with a mysterious, chronic illness is that you really do not know from day to day how she will feel. At Janet's worst, she will tell people she does not know whether she will have one hour out of bed or eight hours or ten hours. We cannot really plan anything. As a husband and caretaker, one has to be very flexible. It's hard to work a regular job.

As she became sicker, I realized that I needed to do more and more of the daily household routine. We have a young son who is nine now.

At the worst of it, I was doing two-thirds or three-quarters of the childcare, working full time, and helping Janet as best I could. My work with the local meditation occupation as well. I attend meditation periods and meetings wherever I can, but my ability to be there depends on the needs of my wife and child.

Meditation is not a quick fix to any emotional or physical problems. In addition, it is not always obvious what is helpful to her and what is not. In my case, I do not have another version of me who did not do meditation practice for twenty years, so I do not know if that other guy might have had a much harder time than I have.

My sense is that since I have practiced meditation for all these years, it is much more possible for me to be patient and especially humble through this process. I believe patience and humility are two of the more important qualities for a caretaker. What has been helpful for me as well in my study of Zen meditation is the realization and acceptance of the limits of our knowing what to expect, knowing what we can or cannot control.

We are very complicated, smart people. We have all lived on this earth for thirty, forty, sixty years or more. We know a lot about certain health issues and ways to cope with them. However, our knowledge stops at the edge of our consciousness. Beyond that, we just are not on very solid ground.

Since this illness is not fully understood by medicine and science, I have to be careful about thinking I understand what is happening with Janet. I need to practice flexibility in my thinking in order to be open to her expressing her feelings and concerns to me.

For instance, one of the things I have discovered that is *not* helpful,



and which has been hard to let go of, is when Janet would appear to be feeling better. She might have had a few good days in a row and I would get very excited. I would start talking about the future, of how she is getting better, and about all the things that are now possible since she is feeling better. I would quickly begin to feel relief and excitement that maybe NOW she is on the mend and we can go back to how we were before she became ill.

This was not helpful. It produced many expectations of what was supposed to be happening, when in reality we did not know what was happening. If she felt terrible the next day, it made it all the worse.

She finally had to tell me to shut up, to not get too excited and begin making plans for us when we really did not know what the next day could bring.

There is a moment-by-moment quality in helping someone with a chronic illness. Meditation practice does help you notice when the mind is grabbing onto a new *story line*. We all have story lines, but most of them prevent us from really being present and helpful, especially if we jump from one to the other and hold them too tightly.

It's easy to shift too quickly from the story line of "Oh, she is never going to get better. This is terrible. What a hard life I have and what a

hard life she has. I should be more sympathetic...”; and jump from that narrative to “Oh, this is great! She is getting better. Everything is all better. I am going to get out of this now and we are going to go back to how we were in our twenties!”

Such thinking is not helpful. Meditation gives me a little spaciousness in my mind, so I am more likely to notice when I am shifting my story line around. It helps me to recognize that I am not living in the moment; rather, I am inventing a future that may or may not happen.

That is when I need to ask myself: “What is actually happening right now? How can I be helpful right now?” Chattering on about new stories is not the best way to be helpful. It is usually something much simpler, such as: “Can I get you a cup of tea?”

Would you like me here with you or would you like to be left alone?”

Q. I have known you and Janet for many years. When you were both young, you were very active. Since Janet’s illness that has all been curtailed. There have also been the significant changes having a child brings to your mobility. I can see where either mourning the loss of all you used to be able to do, or, when she feels better, jumping into future planning, can create tremendous confusion.

A. In a very overt way, we can see the set-up for the suffering, which is one of the core truths of Buddhism: How life is characterized by suffering through our attachments to those things that do not really exist, and to not living in the moment.

That is absolutely true. When people hear that attachments are “bad,” that sounds like you are not supposed to love anybody or want anything. That is not exactly what Buddha was saying. Working overtime to try to change a situation you have little control is not the goal.

What he truly meant was to **notice the mind**. Pay attention to what is going on in the mind. You notice that it is much easier to see your mind when you have some time to sit quietly. As you look at your mind, you see that whenever you are desiring something in your life to be somehow different than what it is in this moment, then there is a lot of extra trouble. Even that can be easily misunderstood.

This idea of non-attachment to desire is not to say that one cannot change or have goals or move forward on those goals. The natural tendency of the mind is to wish for things to be different, to yearn for

things that do not exist. The big problem with this tendency is that it walls you off from appreciating what actually is.

If you are in a primary relationship with somebody who is ill and you love each other and there is a connection (and there must be if you are taking care of the person), there is something very beautiful there. There is something deeply rewarding in that situation. If one is too much involved with thoughts of how things should have been or could have been or were or might be, then you are not able to access that feeling. Then where are you? You are nowhere, and then you feel disappointed or feel you have failed.

I recently did a short introduction class on Zen. One of the more poignant comments that someone said was that Zen seems like such a sad belief, a sad way to live if you believe everyone is suffering. Her particular definition of suffering differs from the Zen Buddhist interpretation of suffering, which is not “Oh life is miserable. I just have to suffer and somehow I will be rewarded in another life.”

This is a very Judeo-Christian orientation. I explained that in Buddhism suffering doesn't mean that we labor under a horrible yoke of burden, but rather that life is simply suffering because we are disappointed at times. We do get sick eventually. We do lose the people we love eventually. We will die. Those are just eventualities we cannot prevent. How we learn to live with those facts, how we learn to cope with the reality of those things, can change the suffering.

According to the four basic truths of Buddhism, attachment creates suffering not because one loves, but rather because one wants the world to be the way one wants it to be, instead of accepting the world as it is. The third and fourth noble truths involve finding liberation, that path of peace, through accepting that this is what it is and one can work with it. I can work with it. This isn't something for me to necessarily bemoan and shake my fist at the universe for being the way it is.

Q. Some people do not understand that very first important truth of Buddhism, which is about the suffering. Like the person you just mentioned, they see that acknowledging the inevitability of suffering as somehow giving up. What is your interpretation of the path to peace, the four noble truths that we are eventually encouraged to understand through meditation?

- A. What I recommended is to consider the possibility of seeing one's difficulties as opportunities—opportunities to learn. Essentially our response to trouble and difficulty is to avoid understanding the mind. It is helpful to add one more word to the first truth, also conditioned. Life is influenced and controlled by our desires, our aversions, and our fantasies. Life is suffering.

Where that comes into play for people working with chronic illness is that the teachings of the Buddha turn something on its head in an important way. What these teachings change for us is our reactivity toward illness and the attempts to get rid of it. There is not anything wrong with getting rid of difficulty, but that impulse is so deeply ingrained in us, so habitual, that by running from difficulty we wind up not seeing what actually is. That is the disconnect that creates suffering. I think that that is a large part of Western psychology; that is where denial comes missing if you are not “happy”. Well, maybe you can enter into peace and a happier life through difficulty, through working with or through difficulty.

We all know people, and sometimes we have experienced this ourselves, who are under tremendous strain, who have terrible illness and are really suffering, and bear it with beauty and dignity. They are somehow able to turn that around into something positive. They have a glow and beauty to them. I think if your difficulty is so serious that it is completely unavoidable—you have an intense illness and you are in pain a lot—most people will discover naturally on their own, with or without spiritual training or guidance, that there is no escape here.

The only way forward is through this, to really feel this pain, to understand it as an experience and come out the other side of it and to realize, “I can bear this. Amazing! I did not think I could bear this and it appears I can.” Therefore, even though I am in pain and I do not like this—I wish I did not have this condition—I can see through that difficulty. It is somehow okay.

That is turning toward difficulty and entering into difficulty. It is hard to do. It is easier with support. It is easier with some kind of spiritual practice like meditation or prayer. That is the important implication of the four noble truths for people with illness. Can we train our mind and practice? You try and try. See how you are reacting. Then try again. Can we practice turning toward difficulty and entering into the painful situation that is happening? You breathe and really feel what is

going on in the body and really feel and develop some awareness of it, then what happens very naturally is that sort of spacious feeling arises.

If you are able to see fear or pain as a sensation or as a thought or as an emotion, it opens up something very important. Then, there is somebody seeing the fear. You can be outside and inside your fear and pain at the same time, so you are not so consumed by it. It doesn't run you and cause additional suffering and pain. You can enter into that difficulty with awareness and be able to see it for what it is.

I think the spiritual practice of Buddhism does not make a distinction between physical and emotional suffering. It is all one human life.

I was talking with someone the other day. She and her family were healthy. But a friend of her eight-year-old son is dying of leukemia. She said to me: "I do not know what to do with these feelings. I cannot bear these feelings. It is just too upsetting. I can't face it. I can't bear it."

What I realized was: Well, you can bear it. You are bearing it. You feel some feeling. You are telling me about it. You are not losing yourself in some other activity. You are not doing something unhealthy. You are bearing this. There is a possibility here to enter into that feeling more deeply and come out the other side. Even though something terrible is happening—this child is dying—entering into the difficulty helps us realize that our potential as human beings is much more vast and spacious than we might have thought. Sometimes it takes a really bad condition to feel that in our bones. I would not want to wish anyone a terrible illness, but good things can come from anything.

Q. My spiritual practice over the past eighteen years has helped me. I did, indeed, suffer deeply for a long time. Not so much suffering the pain of the disease, but the suffering I added on top of suffering, the way I interpreted the suffering, the labels I gave it, the suppositions I made about how other people see me—all that shame and fear in my mind about what this disease means to me. Zen practice has helped (for the most part—I still have a ways to go) to realize:

Fact: I have a disease.

Fact: There are things I can do about it, but I can't cure it.

Fact: This disease is not my identity, only one of countless facets of my body and mind.

The nonfactual, or what I call adding suffering on top of suffering is the “meaning” I give to it: This means I am deformed. This means I am not as good. This means no one will see me as good enough.

My husband often serves in a role as caretaker—he is a healthy man who has a chronically ill wife. How he chooses to interpret and respond to my bad days versus good days also increases or decreases his suffering. There is always a certain amount of suffering, because he has a compassionate heart. He will always wish that I didn’t feel the pain I have to feel at times. By not adding the “isn’t this awful” piece, he has a much easier time of it. He also frees not only himself but me from the guilt of seeing him suffer. Without that attitude, the relationship between the caretaker and the ill person can be a vicious circle.

- A. Meditation practice over time has helped me realize that physical and emotional pain can be very complex or fairly simple, depending on one’s view. Not to minimize any one’s experience, but I found I can choose to view my own pain in different terms than I might if I had not learned about Zen practice.

If there is a pain in the body, we tend to tense around that and try to turn away from it, assuming that it is just going to hurt like the dickens forever. That is the place where we can really shut down and feel overwhelmed.

Meditation practice gives you the combination of ease and discipline so you can gently and steadily focus your awareness while you are meditating, examining the perception of your discomfort or pain, rather than just reacting to it.

Oftentimes it helps to use the steadiness of breathing, feeling your breath, while also turning your attention toward strong sensation or pain. As you do that, little by little you see, “Oh, it is not just one monolithic, overwhelming sensation. It varies. It moves around. It has different temperatures. It has different emotional colors. Then look, it is not actually there for a moment. Now it is back.”

Every time a new, difficult physical sensation arises or a difficult mental or emotional experience arises, we tend to put a wall around it because we think it is too much. We cannot deal with it. It is too huge

and unbearable. As you turn toward these things and study them in some detail, they are actually much more varied and interesting in a way. Like everything, they come and go. That is another core teaching from Buddhism. It is so simple, something we all know.

Often, we do not live in accordance with this: **there is impermanence and change.**

Q. I know that the degree of pain itself can change over the course of ten minutes. It is amazing. This understanding is one of the profound things Zen has taught me and has brought some relief to my pain.

A. Zen talks about how this understanding is already in there. You just have to open up to it. Zen helps me open myself up to that understanding. Even when I am at my most miserable, I can just remember that this is going to change, that I won't feel this way in a day or two. It is an incredibly powerful, moving teaching that Buddha gave us. Nothing has to stay the same. That is important to keep in mind and to hear.

Also, through putting in the time to meditation practice, you experience this more and more clearly, and it is a lot easier to remember. Good teachings are very helpful, but even more helpful is to experience it yourself directly, with some support, so you can see these patterns.

The other way turning toward mental and physical sensations helps us is that when that thought arises—that feeling of being overwhelmed, of not wanting to ever get out of bed again—you can turn toward that thought and say: “Oh, an overwhelmed thought is arising. A feeling of defeat is arising.”

You realize that is just another sensation. You can then return to what is actually happening. You are lying in bed or sitting in a chair. You are breathing. You have this certain assembly of sensations going on. Thoughts are going to come and go and also change. You don't have to be pulled around by the nose by your thinking—not to say we are ever going to stop thinking or that our thinking is not convincing. Our thinking is very convincing. That is what the brain does. It is also possible to see that thinking, in a broader context, arises according to conditions, so it is natural we will feel overwhelmed and not want to get out of bed when we are really hurting. Although that is not exactly true either. It is and it isn't.

Q. How does one get started and empty the mind of all thoughts? How can I relax, slow down, when my mind is still running on overdrive?

A. That is a great question. That is fantastic. You are practicing. You are relaxing. You are aware of your mind. That is pretty much the whole thing. One of the things that happens when you take up meditation practice is that you are more aware of what is normally happening all the time. So, that fast mind is running in a way it needs to run. It is arising according to conditions in your life.

Little by little it is possible it might slow down a bit—or it might not. The point of meditation is not so much to achieve any particular mental state or to modify the way the mind is working. It is the practice of actually noticing what is really happening, and that is liberating and powerful. When that light of awareness shines on your consciousness, you have some leverage. You have some possibilities that you actually did not have before. When your mind was running, and therefore you were running, it was all happening on autopilot, by habit. There is nothing exactly wrong with it, it is just what is going on. To be mad at it can be a little disconcerting.

Sometimes people are a little frustrated by meditation. I don't want anyone to have any false hopes of instant calm and total joy. Meditation can be a little bit challenging. You see what is going on. Sometimes what is going on is very agitated or very nutty or very crazy. One thought links to another. You see these endless chains running around. Little by little, it typically settles down. Over time, it becomes less unsettling.

The mind is always running. Instead of saying, "What a bad meditator I am. I'd better listen to that call-in show and figure out how to get my mind to stop," little by little we can just see the mind for what it is. It is a thought-creating facility. To criticize it for thinking too much is very much the same as being mad at the way the body and the reflexes change as you have Parkinson's. That is just the way it is. Things are happening the way they are happening. Luckily, a nice side effect of consciousness and awareness is that over time it gets less nutty and, most importantly, you are not as bothered by it. It is actually a little funny after a while.

Another thing that can help with this—there is no magic bullet in life, but this is pretty close—is **awareness of the breathing**. This seems to be helpful in just about every situation I can imagine. Breathing is always with us. It is an automatic response. Every second of living we are breathing.

Breathing has some beautiful qualities. It has rhythm, pattern and warmth, moistness and softness. In meditation practice, or any time, turning awareness to a soft and gentle focus on breathing is very calming and steadying. It is the one companion you are always going to have. When your awareness gets pulled away by your fast-running mind, it can be helpful to notice that and circle back to the breathing. Exist in the sensation of breathing for a couple of breaths. Don't be too upset when the mind yanks you forward again. Notice that. Return to your breath.

One way to think about meditation practice is as a process, building mental and spiritual muscles that allow us to not be carried off into distant lands by our fast mind. Meditation helps us notice that process and return. That is helpful when we are having very strong physical sensations, too. Notice the sensations. Notice what is going on. Notice that we are upset. Notice that people around us are upset. Then return to the breathing. Return to simple, bare awareness of the actual sensations. Breathing can be helpful with whatever is going on beneath.

Q. How much does posture have to do with meditation? Some people ask, “How can I meditate when I cannot sit still or I have constant tremors?” Can meditation be done stretched out flat instead of sitting? Can one practice with tremors?

A. Yes, meditation can be done stretched out flat or with whatever else is happening in your body. The important thing is to find the best posture for your body in its current condition, where you can have some stillness and some stability.

For able-bodied people, it is helpful to sit upright either in a chair with your feet planted on the floor or in some kind of cross-legged posture with a pillow under your rear to raise your back up a little bit. If that is painful or difficult, do not try it. Don't force yourself to do something your body is not currently able to do. Lie down or recline.

First, relax as best you can. It is a different kind of relaxing than going to sleep. It is a relaxation with clear, bright awareness of what is

happening and of the sensations in the body and mind. Get stable. Get reasonably comfortable.

Then a good way to start is to slowly scan the body, starting at the tips of the toes, noticing the sensations in the body in the toes, the feet, the legs—really noticing, not just thinking. Try feeling each part of the body without getting too upset or trying to fix anything, noticing where there is more or less tension or discomfort. Scan the body to establish a sense of awareness so that you are not sagging but are as straight in your spine as your body will allow. It is a very different experience than being a couch potato, though the posture might be very similar. The posture can be adapted to whatever is going on with your body.

Once you have a sense of where you are, where your body is, and what you are actually feeling, bring your attention to the breathing, especially to breathing low down in the abdomen.

If you exaggerate your breathing for a minute and take some deeper breaths, you notice that when you inhale, there is a muscle called a diaphragm that squeezes, opening and closing your lungs. When you inhale, the diaphragm is expanding and there is a sense of rising. When you exhale the diaphragm relaxes and there is a sense of falling. That is a good place to notice the breathing. Bring your attention gently down to the abdomen, to the very center of the body.

So much of our agitation and worry happens when our thinking and consciousness are overly identified with the frontal lobe of our brain. When we think, we are in our forehead, leaning into our life, worried, trying to figure everything out. It helps to shift the center of awareness from the center of our *being* down to the center of our *body*, to the very stable, quieter place. There, notice the rising and falling, feel that and breathe with that. There are some concentrations and various techniques you can do. One is to stay with the exhalation. Let yourself sink, drop, into the exhalation. Let everything go with every breath. The exhalation has a sense of relaxing, dropping, and just letting things become a little more still, a little more quiet. On the inhalation, feel the new energy coming in; that there is the possibility that anything can arise in every moment of our lives.

Part of how our typical story lines victimize us is that we think: “This is my fate. I am stuck feeling this way. This is it. I am always going to be exactly as miserable as I am now or maybe even worse.”

When we feel this way, meditation can help us. It gives us this sense that, with every breath, everything can, if allowed, completely vanish into nothing: can float away on our next exhalation. If we can experience that, even for a fleeting moment, we have opened up the possibility for whatever the next moment is going to be. Having that sense of letting go, of release and newness, is very different from how we are taught to live our day to day lives, where often the new and unknown is seen as frightening.

When the mind gets agitated or a strong sensation arises, something happens. We are hopefully in a pretty quiet place. There is nothing obvious going on. Still, all kinds of things are happening. They can pull us away from ourselves. We may lose the sense of release and possibility that is in the breathing, especially this gentle awareness of the breathing in the belly at the center of the body.

When that happens, we get sucked into a chain of thinking or worry or doubt or excitement. We can notice that and turn our consciousness toward that: "Oh, I see that." We can put a label on it: "Oh, I am anxious. How about that?"

You can just notice that and return to the present moment of breathing and any other sensory perception we are aware of: the breeze through the window, traffic outside, the light or shade as sun or shadow pass by.

Q. Some people wonder if there is an optimal amount of meditation they should do each day to help better manage their disease or pain. Do you have any thoughts on that?

A. It is far more effective to mediate for a short time regularly than not at all. Five or ten minutes every day is fantastic. To summon up all your energy to meditate for half an hour or an hour once a week is sometimes not nearly so effective, depending on your body's condition.

The other thing that is useful is to find some cues in your life to remind you that this is available to you. It is possible to do this. One of the big difficulties of chronic illness is your schedule goes out the window. I have certainly noticed that with my wife. I do not have a regular schedule where I am going to get up at this time and practice my meditation at that time. That is a luxury for healthy people, or healthy people not affected by a loved one's illness. For people who are

in the unpredictable situation of chronic illness, look for other cues in your life than can remind you to make some time for meditation.

With chronic illness there is tremendous amount of waiting. You are always waiting for the doctors, or for this or that. Instead of just waiting and letting the anxiety or boredom build, maybe waiting itself can be a cue for you, a reminder that you can practice meditation.

Q. What are some of the differences meditation has made to people with disorders such as Parkinson's or arthritis or any chronic pain problem? I realize that may be difficult to quantify.

A. The roller coaster ride of chronic illness is one of the hardest things for people. See if you can practice mediation on the days you are feeling a little better and on the days you are feeling absolutely rotten. It can give you the gift of something in your life that has some sense of continuity and stability. The background of chronic illness is wildly unpredictable and difficult.

When the body is in those states of crisis, the body pumps out adrenaline and other related hormones that create tension-provoking, anxiety-provoking fears. Many people find that meditation is really a great solution for this.

Our spiritual practice can only happen under current conditions. When the body is in crisis and things are difficult, the caveat to stability and steadiness is that it might actually be impossible to notice your breathing for five or ten minutes. You do the best you can. You practice a lot of flexibility and gentleness with yourself. Current conditions might be that it is possible to notice just one breath. That is fantastic, if that is all that is possible right now. We have to watch out for the tendency to associate mediation with results.

We always want results, which is part of where we get into trouble. Chronic illness is not what we wanted. That focus on results might mix us up. When we are feeling good at some point in our practice, meditation might be very peaceful.

Maybe you will have a period of meditation where it is very calm, spacious, and beautiful. But do not carry that as the gold standard. Do not feel like, "Oh, now I have attained a good meditation. If I cannot repeat that experience, it is more evidence I am a failure. I am not

doing this right. I should give it up.” That is just a response within the context of what is going on.

Meditation helps, no matter if it seems like nothing is going to happen. If things are really rocky, your meditation is not going to be so peaceful. You might feel horrible. Have faith in the steadiness. Even if it feels awful and it is not what it was yesterday, give it a try. See if it will help, over time, to spend a minute or five minutes doing your best, very patiently, very gently, and with a lot of forgiveness and humility.

Just bring your attention back to what is actually happening—to the sensations in the body, to what is arising in the mind as thoughts and emotions—and especially to the breathing, the central fulcrum this turns on.

Q. I know of a man who is an ecologist and, as a scientist, believes nature has dealt him a bad hand by giving him Multiple Sclerosis. He believes there is nothing he can do about it except to keep fit as long as possible. He has always pushed himself to the limit and prided himself in his achievements. This has hit him very hard. He is very skeptical about any promises of help that may cost money. He thinks someone is capitalizing on his misfortune. How do you think meditation can best help him?

A. That is the question for all of us. How can we help somebody who, from our point of view, is in difficult circumstances, is suffering, and has an attitude that causes them some rigidity and additional pain? It looks as if this person is putting a scientific head of pain and destruction on top of his head.

The first thing you can do to help him is to try these practices yourself, not as a way to convince him or to test them out before handing them over. Trying these practices out adds validity if you offer to share your experiences with him. See if you can be yourself, be a little more present, a little more patient, a little more open.

We really want to help the people we love. We really want to help our family. It seems like that usually suggests to us that we should run around and buy them things, figure out solutions, take them to a new or better doctor, etc. That is part of what we think we need to do. However, that only gets us so far. They might not want those things

we are offering. The problems might not be something we can fix in this busy and productive way that we go about things.

It might be that the best way to help this man is to practice being with him a little more quietly, a little more gently, with a little more space in your own heart. Sometimes real possibilities arise out of that: just having someone be with us, listening to us, being kind to us, not trying to fix us or figure out the problem, or convince us that they have a better approach. That itself can be very healing.

Sometimes what happens—not that we are looking for this result—but sometimes if the caretaker practices meditation and the relationship shifts, the other person wakes up one day and says, “You are so much calmer and nicer. What is going on here?”

Then there may be an opportunity to say, “I have been trying meditation.” Maybe that will never arise.

I would not buy him meditation tapes. I would not tell him that his views about science are misconstrued and cause him pain and suffering. I would not be dishonest. I would say: “I hear what you are saying. I do not totally agree with you. My priority right now is not to have a debate with you. My priority is to be with you and support you in any way we can think of and in any way I can. I love you and I am completely here for you. That is my only agenda. I am doing my best to let go of any other agendas I have. I just want to be present and support you. I am trying to practice being open to whatever happens. These illnesses unfold in very unpredictable ways. We have been reading up on it. We do not know what is going to happen. Let’s enjoy our time together as best we can.”

We get so involved in trying to fix everything. It comes out of a beautiful impulse. It comes out of love. It comes out of a desire to help. But sometimes that desire to fix becomes very overbearing and completely backfires. It just makes the person feel worse. Not only do they feel bad, they have this terrible disease, they have the ideas about this disease, and they have to fight you off, too. What a burden that is!

Q. There is some scientific evidence that when you change your breathing patterns, you change your blood chemistry, and thus change your neurochemistry. The change occurs when you change how you breathe. As a psychotherapist, I often work with anxiety patients, helping them learn to breathe

as the anxiety starts to hit—to inhale for a certain count and exhale for two or three counts longer. Do you think it is physiologically changing what is happening inside our bodies?

- A. In essence, it is all pretty simple. As educated Westerners, we think everything has to be really complicated to be valid. It has to involve clinical trials and people with PhDs. Actually, just breathing can be hugely effective.

The other suggestion I have is to involve somebody outside the dynamic. People close to us might listen to someone that they are not used to hearing advice from, such as a therapist or yoga teacher. It is a difficult situation, no doubt about it, to watch someone you care about suffer.

It is important too, to recognize that the person suffering is not the only one with the problem. Those close to him have a big problem, a challenging situation. You cannot forget about this loved one. You want to help him. It is difficult to help him. To feel that and get support and take care of yourself is also an extremely important thing to do. This is as valuable as anything else you could be doing.

If you are a wreck and not taking care of yourself, it is going to be that much harder to be present for someone else. To recognize the tendency to deny our own self-care in favor of caring for someone else is essential. It is a very powerful impulse. If we give in to that impulse, we not only weaken ourselves, but also our ability to continue taking care of the loved one who needs us.

The psychodynamics of that are incredible: the sense of guilt, resentment. Suffering on top of suffering on top of suffering. Then you have this circle of suffering. That is when bringing in and experienced third party can be very useful.

Q. A therapist friend of mine has consulted about a client who has Parkinson's. She told her therapist that when she meditates or when she is sleeping, her body does not move at all. She wonders how she could bring this to her everyday life to stop the tremor?

- A. Perhaps by allowing awareness of your body in meditation she can become more aware of the sensations of the body. Meditation is not about the absence of sensations. There is a quality and

flavor to the sensations that is strongly marked by stillness and silence and calm. If you practice breathing and doing the body scan, and become more deeply familiar with what the feeling is—to really feel the feeling in meditation—little by little, it transfers to your waking life and your moving life.

Q. Some people have asked me about different remedies they have seen on TV, or heard through well-meaning friends, that are often expensive or have no basis in scientific fact. What would you tell them?

A. I would wish everyone well. It is not easy being a human being in the best of times. It is challenging. It is a huge thing if you have a chronic disease or are caring for someone with a chronic disease. You may think the suffering should go away if you have the right technique or device or pill, and that you should somehow feel better about it. It is difficult. Be very patient.

Also, the practices we have been talking about can help. Give them a try. See what you think. Most interesting to me from doing spiritual practice is the realization that a very small shift in attitude can be hugely transformational. You can't think yourself into a shift of attitude. You actually have to do something. You have to change something. Do some kind of practice. Each person with their own body and own circumstances has to figure out what that is. If you do something that shifts your attitude about your illness just a little, it is possible to feel a lot better about it and have much more ease in your life. Good luck. Sometimes a very small thing can make a very big difference.

Q. Tim, if people would like to learn more about your meditation teachings, how can they get in touch with you?

A. You can access our Red Cedar Zen community's web page at www.redcedarzen.org

On the site, you will find talks and teachings given by myself as well as other teachers in the sangha. You can also find out about retreats and other activities related to meditation, including introductory classes if you are unfamiliar with the process.

- Q. Tim, thank you so much for sharing your understanding of meditation and the difference it can make when loving and caring for someone who is chronically ill. You truly demonstrate how mindfulness can make such a positive impact on the love, nurturing and safety a couple can experience with one another when they live together in the reality and acceptance of the illness. Is there anything you would like say to other caretakers in closing?**
- A. Be as humble and present as you can. Be informed. Try not to fix things. Just respond to changing conditions as best you can. Do what you need to do to take care of yourself and touch the deep feeling within the relationship. That is what is nourishing. That is why you are there.
- NW: For an in-depth and beautifully written biography of Suzuki Roshi, please see David Chadwick's *Crooked Cucumber*, Broadway Books, New York; 1999.)



Avalokiteshvara—the bodhisattva of
compassion/loving kindness.



David S. Zucker, MD, PhD

Cancer as Living Dharma

David Zucker is medical director and program leader of Cancer Rehabilitation Services at the Swedish Cancer Institute in Seattle, Washington. In addition to his training as a rehabilitation physician, Dr. Zucker holds a doctorate in clinical psychology. He has been a Long-time student of meditation, including formal Buddhist monastic training, and integrates his interest and practice of meditation into his work with cancer patients.

Dr. Zucker earned his medical degree from Stanford University and his PhD from the Professional School of Psychological Studies. He completed residency in Physical Medicine and Rehabilitation at the Mayo Clinic, and did a post-doctoral fellowship through the Department of Rehabilitation Medicine at the University of Washington. He is board certified by the American Academy of Physical Medicine and Rehabilitation.

Q. Please tell us about your background in meditation.

A. In my twenties I began investigating meditation and attended retreats with Joseph Goldstein and Jack Kornfield. They had recently come back from Asia. I learned about practices that were coming from the East. I experimented with many spiritual practices. In the mid-1970s, I came across Vipassana meditation and did a continued study with various teachers across time. I was living in New Mexico at the time. My first retreat was at the Lama Foundation in Taos, New Mexico. It was truly a profound experience. I took up the practice and I have been interested in meditation for a very long time.

It really goes back to before I knew what the word meditation meant. At five or six, I used to lie on my back at night and stare up at the sky. I could be here and “there” was “out there.” As I grew, the questions matured. I wondered whether I could trust my senses to give me an accurate portrayal of reality. This evolved into wondering what it meant to be human and humane.

I have interest in both Theravada and Mahayana Buddhism. In the early '90s, I moved to Seattle, stumbled across Zen, and became a student of Jack Duffy Roshi, a Dharma heir of Robert Aitken Roshi. I also studied with Rodney Smith (Seattle Insight Meditation Society). Rodney's monastic training was in Thailand with Ajahn Buddhadasa. In the late '90s, I ordained at Harnham Buddhist Monastery (Aruna Ratanagiri) in England, under the guidance of Ajahn Munindo. Ajahn had trained with Ajahn Chah in Thailand. The year of monastic training was a major turning point, as the various teachings and traditions continued to speak to each other in my practice.

Q. You have a doctorate in psychology and are also a medical doctor. Were you practicing meditation before you chose the healing arts as a career?

A. I was practicing meditation before graduate school in psychology or medical school.

Q. In your professional training, was there any conflict between what you were being taught in academia and what you were learning in your meditation practice?

A. I don't think there was anything I learned that was antithetical to meditation practice; at least I didn't take it that way. I was amazed by the passion, energy, and knowledge of scientists and clinicians in the lineage of those who have helped us understand and treat body and mind in health and illness. My amazement continues to deepen as I continue to learn. So much in Western medicine and psychology works so well.

Q. Did your meditation practice help shape your professional training?

A. Yes, in many ways, it did and continues to do so. In my practice, I began to get glimpses of how thought patterns arose and passed. I recognized thought patterns as a kind of filter through which my sense of identity and my particular understanding of the world arose. I began to see that my own thinking was often distorted and that these distortions had an enormous influence on how I experienced "reality."

Early on in psychology graduate school, I came across phenomenology. I started reading Edmund Husserl and Maurice Merleau-Ponty. I was fascinated to learn that their inquiry was directed toward understanding the nature of human experiencing. This struck a chord with me. It actually was quite surprising to me.

Phenomenologists explore the "taken for granted world" by asking, "What is the nature of human experience? How does 'the world for me arise'?" The phenomenologists posit that our own history, sensate experiences, and related thought patterns combine to create the experience of "the world for me." We take that world for granted, but is "my world" reality?

These questions were congruent with what I had been exploring in meditation practice. The difference for me between meditation practice and phenomenology was that the context of phenomenological inquiry is the intellect—thought—whereas the context of meditative inquiry is awareness. With sitting practice, I had the fleeting awareness that thought was a kind of sensation. I began to understand that the world that I took for granted wasn't fixed. This shook the ground under my feet. Without sitting practice, I don't think that I could have understood this, although I am certain that others have this insight without formal sitting practice.

Later, in medical school, I was introduced to Dr. Irvin Yalom, the existential psychotherapist, and had the good fortune of working closely with him. In his work, Dr. Yalom explores in beautiful ways what he calls the *four ultimate concerns of life*: that is, death, freedom, existential isolation, and meaninglessness. For him, the underpinnings of human distress are rooted in the internal conflict that arises in response to these ultimate concerns. The healing power of the existential approach to psychotherapy lies in explicitly focusing on and addressing these four concerns. He also explicitly calls out the profoundly personal nature of the therapeutic relationship and the ineffable, tender qualities that make it healing.

I saw a direct link between Dr. Yalom's work and what I was learning from Buddhist practice. From the Buddhist perspective, we are all subject to sickness, old age, and death. The Buddhist way of framing these realities parallels Yalom's articulation of *ultimate concerns*. In addition, Buddhist practice, like Yalom, points us toward the paradox of healing: by turning toward distress you find well-being.

So yes, meditation practice helped shape my training. It provided a meaningful framework against which to contextualize what I was learning. Equally important, the practice helped me cope with the rigors of professional training. Meditation continues to have a profound influence on my work as a physician. The view into *ultimate concerns* that meditation practice offers continues to help me integrate my understanding of suffering into the critical thinking skills I use—and continue to develop—in day-to-day clinical practice. My practice of meditation and my practice of medicine go hand in hand. As time passes, it is becoming more and more difficult to distinguish one from the other.

Q. Would you please tell us about your medical practice at Swedish Cancer Institute?

A. Well, first of all, I am a rehabilitation physician. The official name of this specialty is **physiatry**, not be confused with psychiatry, although often people do. The goal of rehabilitation medicine is to restore optimal function and quality of life to people with physical impairment or disability resulting from illness or injury.

My subspecialty in rehabilitation medicine is oncology. My psychology training helps me address the emotional, psychological, and existential impact of cancer at the same time that I am addressing the physical impact. My medical practice is limited to people who have cancer. It is an outpatient practice at Swedish Cancer Institute in Seattle, Washington.

I am a member of an interdisciplinary team of medical oncologists, cancer surgeons, radiation oncologists, social workers, psycho-oncologists (psychiatrists who specialize in working with cancer patients), nurses, physical therapists, occupational therapists, speech language therapists, and naturopaths, not to mention a host of administrative and support personnel. We also offer a variety of support services, including music and art therapy, support groups, biofeedback, mindfulness meditation (modeled on Dr. Jon Kabat-Zinn's program), and nutrition classes. I could not do what I do without the team.

I frame my interest in meditation against the backdrop of training in Allopathic medicine and Western psychology. I prescribe medications and order diagnostic tests when needed. I read and interpret pathology reports, consult with the other oncology specialists, and coordinate care amongst health-care providers.

Q. How does your experience of meditation play into your work as a physician caring for cancer patients?

A. When a person is diagnosed with cancer, it is often the first time they recognize that life not only has a beginning and middle but also has an end, and that end—death—is personal. There is suddenly the awareness that “mortality applies to me.” That experience is profoundly unnerving for most people. The destruction of innocence creates an existential friction that is enormously painful; it is difficult to deny.

You can imagine: you are going along, you are feeling fine, nothing in your life is particularly problematic, you go to the doctor one day because you find a lump somewhere in your body. “I have this little bump here. What is this?”

Your doctor sends you for a biopsy and, later, you get the phone call: “I have bad news. You have cancer.”

All plans, everything you imagined about the future, comes to a stop. You can't hang your hat on the future you imagined for yourself.

You are left in a state of free fall, spinning in the universe with nothing to hold onto. Where do you go? What happens? For many people, what happens is akin to what happens when the mind is very calm and still. The deeper truths about what it is to be human, the facts of life, arise. They cannot be denied because your circumstance so powerfully and directly puts you in contact with them. This experience can dramatically change one's way of viewing life.

Dr. Irvin Yalom puts it well:

A confrontation with death often creates a dramatic perspective alternating opportunity. The German philosopher Martin Heidegger spoke of two modes of being. The first, an everyday mode in which we marvel at the way things are in the world. This is a state of forgetfulness of being, a feeling of being tranquilized by the cornucopia of objects surrounding us. The second is an ontological mode, a state of mindfulness and being in which we live authentically and marvel at the very 'suchness' of things. In this state the individual is primed for life change.

How do we move from the everyday state to the ontological state? The German psychiatrist and philosopher Karl Jaspers describes a major vehicle as the 'boundary experience', a jolting irreversible experience which shifts the individual from the everyday mode to a more authentic mode. Of all the possible boundary experiences, confrontation with death is by far the most potent. Time and again we see individuals who, in a confrontation with death, make dramatic life changes.

It is a familiar theme in great literature. For example, Scrooge in 'A Christmas Carol' and Tolstoy's Pierre in 'War and Peace.' Cancer patients have described the experience of re-prioritizing life values, and trivializing the trivia in life, and saying 'No' to the things that are unimportant, and turning full attention to loving ones about them: the rhythms of the earth, changing seasons, concern about the model of dying they set for others. In a macabre sense, cancer cures psycho-neurosis and gives an unmistakable, bittersweet poignancy to life. Still another way to put it is that while the physicality of death destroys us, the idea of death can save us."

Yalom is saying awareness of "my death" drops us into contact with the deeper structures of our humanness. To put it phenomenologically, because something has so dramatically changed in our life—things that we take for granted, things that we would normally not

pay attention to or be interested in—our “taken for granted world” has simply fallen apart, fallen into pieces. You can’t put the pieces back together. Humpty Dumpty is gone.

Q. You are thrown into a whole new universe, although it is not really new. You were just not aware at the time that you were always living in it.

A. Yes. There is a parallel here with sitting practice. When you withdraw some of your attention from the stream of mental chatter and instead gently direct it toward sensate experience—for example, posture or the sensation of breathing—you are voluntarily setting up the conditions for a boundary experience.

Little by little, you get a bit of wiggle room, a little distance between thinking and the awareness that holds it. You are able to simply abide for brief moments in awareness where there is no “me” dictating things, and this leads to insights into the nature of being; or, in Jaspers’ term, the ontological mode.

An example is working with the sensation of an itch when practicing sitting meditation. The instruction is to bring your attention back to body sensation, whether it is your breath, your posture, or the sensation of itching itself. You notice the impulse to scratch the itch. When you explore refraining from acting on the impulse, you may notice an increase in mental chatter such as, “I have to scratch this. It is getting worse. What if it turns into a hive? What if the hive spreads? It could kill me.”

A whole drama unfolds about this little itch. The earth is shaking. There is thunder and lightning. Disaster is pending. If you are able to stay with body sensation in a relaxed way, you may find that you do not need to act to scratch the itch, despite the compelling story your mind is creating and, as mysteriously as the itch arose, it goes away on its own. There is nothing you had to do other than to turn toward your distress with an inquiring mind rather than turning away. You simply refrain from acting on the impulse to scratch it. And, surprise, surprise, you learn that you did not have to control it because it was going to change on its own anyway.

The benefits that accrue across time to this approach to practice are significant. Life changes in surprising ways. For example, you realize that you don’t have to act on every emotional itch that arises. You

recognize that you have some choice in whether or not to act on your impulses and when you realize that, and by skillfully choosing action, you can minimize harm to yourself and others. You are more able to learn from your unskillful behaviors. You unexpectedly find yourself touching the ‘ontological mode,’ appreciating the ‘suchness’ of each moment; compassion, kindness, and wisdom then are able to grow. The potential for realizing such benefits are existential facts no less far-reaching than the existential fact of death. Meditation practice did not create these facts. The practice simply provides a context within which they can arise more or less systematically. These facts have nothing to do with meditation or, for that matter, with Buddhism. It is simply what is so.

Q. It sounds as if you are talking about pure awareness in the moment. Whether you call it Buddhism or mindfulness or just understanding that what is in your head is not exactly outside your head, it is a very profound experience.

A. It is truly profound. You can take it a step further. The mechanisms of life, the way things actually work, are not at all how you thought they were. You don’t have or need as much control as you may have believed. For example, the itch will go away on its own. An operational principle becomes abundantly clear. You can’t explain it. You can’t express it. You just say, “Wow. I had no idea.” Insight into this principle allows one to relax a little bit into the flow of life.

Turning to the experience of illness, a cancer diagnosis sets up the conditions for a radical shift in being, not unlike meditation practice. You may have never heard the word Buddhism. You may have had no interest in anything spiritual, religious, or existential. But you have this enormously powerful shift in awareness that cannot be ignored. It is like when you are riding along on your bicycle and you fall off. Bang. In that moment, everything stops. You are just there with a bump on your head. Now what?

The principle that operates across both meditation and illness is limitation by a boundary. In contrast to the voluntary limitations set up in meditation practice, however, the limitations imposed by a diagnosis of cancer are involuntary. If benefits accrue from voluntary limitations,

such as sitting meditation, there is no reason why they can't accrue from an involuntary limitation such as illness, and they can.

Accepting what arises through the voluntary limitations inherent in meditation practice is hard enough, let alone accepting what arises from the involuntary limitations imposed by cancer. Nonetheless, the inescapability of the illness circumstance often fuels acceptance. You are shaken so fully by the truth of things that you cannot deny them. Denial simply doesn't work; it's like a vehicle without tires. It doesn't go anymore. In my medical practice, I try to create a context that supports the person in recognizing, understanding, and accepting the facts of their situation. In the end, it is really up to the person.

Q. Can you say more about that? How do you integrate Dharma practice into your medical work with cancer patients?

A. It is not that I teach formal meditation in my medical practice. It is more accurate to say that the potential for awakening, while inherent in any life circumstance, presents itself in a highly potent form through the direct experience of the threat to life that cancer represents. I support the person in bringing awareness to their experience.

Simply acknowledging the threat to life can be a good place to start. This acknowledgment validates the person's experience of being in a kind of existential free fall. It can be healing in and of itself because you connect with the person in a very direct way. At the same time, I point to the here-and-now reality that the person has more healthy cells in their body than they have or could ever have cancer cells. People are very pleased to hear this. It offers a small and grounding counterweight to mortality awareness.

Although fairly obvious, when you are living the cancer experience, it is hard not to think that you are your cancer. You identify so closely with the diagnosis. It is hard to believe otherwise. Simply affirming this truth is helpful. What I am encouraging is a shift away from the belief that "the world for me" is cancer.

Keep in mind that, although malignant tumors may harbor explosive destructive power, when discovered they are frequently only a very small lump. The ability to detect a small cancer before it has spread is a benefit of routine screening. As such, early cancer rarely has any detectable impact on normal physiologic function. The person usually

feels no different than their usual self. Physical examination and diagnostic studies are often normal, except, of course, for the small cancer.

I use these facts to further affirm the basic health of the person. If, for example, reflexes and lungs are normal on physical examination, I may acknowledge that out loud. “You have perfect reflexes and your lungs are as clear as bells.” Sometimes I am struck by the sound of a person’s heart. I could just be there, like a baby in the womb. I say, “Your heart is beautiful. I could listen to it all day long.”

Remember that the person is up against their own life. They are facing their own mortality while at the same time you are saying, “In this moment, you are more healthy than sick.” The subtext is that well-being is possible right now.

Once the person has started treatment, a powerful entry point to healing into well-being is encouraging gentle attention to the experience of the body, which is invariably altered by treatment.

Ordinarily, we operate within a relatively bound range of sensate experience and physical capacity. We know quite well what it feels like to be tired, energetic, lazy, in pain, or at ease. We understand how far we can walk without becoming unduly tired, or how much activity we can fit into a day, or how late we can stay up at night without exhausting ourselves. We generally don’t give these limits a second thought and simply act on them more or less unconsciously. They become part of our identity as physically active beings in the world. The physical rigors of cancer treatment, however, serve to undermine the reliability of “taken for granted” physical capacities and sensate experiences.

Let’s use chemotherapy as an example. Chemotherapy is designed to be maximally toxic to cancer cells and minimally toxic to healthy cells. Since cancer cells are derived from the body’s healthy cells, cancer cells and healthy cells are related, like cousins. Some toxicity to healthy cells during treatment is unavoidable, at least at the state of current medical science. Loosely speaking, the healthy cells either expend energy or have reduced capacity to produce energy because of the physiologic demands of chemotherapy. The result is reduced energy for actively participating in everyday life. We call this experience “cancer-related fatigue,” which is perhaps the most common side effect of cancer treatment.

Cancer-related fatigue is different than ordinary physical tiredness after a hard day at work—it impacts not only physical vitality,

but also mental and emotional vigor. During chemotherapy, cancer-related fatigue tends to take a cyclic and cumulative course. Several days after infusion (delivery of chemotherapy into the body), fatigue increases. It gradually diminishes over the next several days, but generally not to the level it was before the infusion. Then there is the next infusion, again with a dip in energy followed by partial improvement. There may be many months of treatment, sometimes one treatment every week. You go up, then you come down.

On top of that, the fatigue adds up, or is cumulative, across all treatments. The body can, in general, cope well with cancer-related fatigue—the resilience of healthy tissue is astonishing. But coping requires physiological work. The body spends energy to help maintain healthy cell function. At the conscious level, the person becomes uncomfortably aware of their body. The dissonance between impaired ability to do things and the desire to continue habitual everyday activities without missing a beat is painful.

Mental and emotional fatigue also contributes to the distress. The impulse is to escape, either by pushing harder to perform physically or collapsing into lethargy. Either reaction increases fatigue, the former through overdoing and the later by loss of fitness through inactivity. Either way, the potential for well-being is undermined.

I validate the experience: “It’s not your cancer coming back. It doesn’t mean that treatment isn’t working.” The key point is that fatigue is simply a fact, neither good nor bad.

Beyond the fact is your response to it. This is where practice comes in. You can help yourself feel better by learning to be in accord with your fatigue-tinged reality. You withdraw your attention from the mind’s proliferation of thought about fatigue and bring it to your body. You “listen” to your body and receive what it is telling you. Since you have the information, you are in a position to act skillfully.

You pause, drop into sensate awareness, and feel into your energy level. Is what you are doing increasing your fatigue? If so, can you change your activity trajectory or take a rest? This is mindfulness of the body. You cultivate a degree of control, not through force, but through harmonizing with conditions. You don’t get your old energetic self back. You get well-being.

Mindfulness of energy goes hand-in-hand with and is prelude to physical training, which can be as simple as avoiding inactivity.

Physical training increases fitness and therefore the body's activity capacities. This is the principle of athletic training. It often comes as a surprise to people that the same physiologic principles apply to "training for cancer treatment" as to training for an elite athletic event, but they do. Athletic training is event specific: there are training principles specific to figure skating, and there are training principles specific to basketball. You can't train for basketball and then expect to be an expert figure skater. Likewise, fitness training for cancer treatment is specific, whether the event is chemotherapy, radiation, or surgery. You have to train based on the particular demands of the event.

Exercise is a kind of medicine. It has biochemical effects in the body, just like a drug. You can overdose or under dose on exercise just like you can with pills. If you push too hard, you overdose and you pay for it. If you under dose, you don't experience benefits. Either way, you undermine your body's ability to find harmony with conditions, moment to moment.

In the oncology world, there is increasing interest in using exercise as medicine during treatment. Research demonstrates, for example, that it is possible for patients who train to increase aerobic fitness and muscle strength to reduce fatigue during treatment, compared to patients who do not train. So we use exercise as one modality in my clinic.

If a person is about to start chemotherapy, I explain that they will likely experience fatigue and that it will be cyclic and cumulative. I say that exercise training can be really helpful, but to get optimal results, you need to listen to your body. It will tell you what the energetic demands of chemotherapy are day to day, moment to moment, and you learn to adjust your training program accordingly.

You let your body teach you what its capacity is at any given moment. There are training principles involved and, along with other members of my team, we are going to teach them to you.

Suppose you planted grass seeds and, finally, one day you noticed little green sprouts in your yard. The seeds had gotten enough fertilizer, enough water. The conditions were right. Little shoots crop up. You wouldn't then take your power mower and go over them! That would destroy them. During chemotherapy, your healthy cells are like sprouts. You learn how to water, fertilize, and give them enough sun based on where they are in the treatment cycle, whether there is a lot of

fatigue or not. You learn to manage that. By acting skillfully, you actually feel better and more confident in living through the hell of cancer and its treatment.

How a person approaches their physical training is just as important as the training itself. I ask people to practice exercise as an act of self-care, of friendliness. This perspective is different than training with a goal, for example, of running faster or jumping further. We are aiming at kindness, *metta*, not athletic performance or human prowess.

You can no longer deny that your life has an end. You now keep in mind that the backdrop for all this is mortality. Cancer has brought with it death awareness. Your ground of being has changed. Your future has been completely upended. You will never finish everything on your to do list. At the same time, you recognize your trillions of healthy, vibrant cells. You learn that, by according to the changing conditions of your body, you enhance your ability to participate in everyday life.

Skillful action inclines you toward well-being, minimizes treatment side effects, and deepens your understanding of your current life circumstances. You find a sense of well-being independent of your cancer. The paradoxical juxtaposition of life and death undermines the mind's ability to create a logical story. The person is ripe for awakening to the deeper structures of human being.

This paradox can become a profound practice for those who embrace it. It is a practice that emerges out of the conditions of the person's life. It is not reading a book about meditation or signing up for a retreat. Life itself has presented you with this painful and rich circumstance. If you can learn to relate to the experiences that arise as a result, you can deepen profoundly.

Karl Jaspers says a confrontation with death is a major vehicle for moving from the everyday state to the ontological state. You profit from facing your own death boundary, but how does this happen? How do you cultivate the seeds of wisdom that are there? I am suggesting that the wisdom teachings point the way, but that ultimately it is not the teachings themselves, but inherent humanness that rises up to meet the boundary.

One of the most beautiful, challenging and profound circumstances is working with people who have incurable cancer and are dying. They know they are dying—the ultimate boundary is ever closer and more confining. One of my patients, a gifted artist, painted and wrote about

her experience of living and dying with cancer. She narrates in image and word, with gentle wisdom, the end of her life. We put together this body of work called “Unexpected Opportunities,” which we have made available for free distribution in PDF format. It can also be downloaded at <http://bit.ly/cw8WVI>.

Q. It sounds as if you approach your patients not just as ill or dying people, but as teachers.

A. Well, yes, as teachers, but also as *us*. We are in the same boat. I recognize that the playing field level is level—I am no different than the person sitting across from me. I, too, am subject to sickness, old age, and death.

Right now, in this particular circumstance, the person I am treating is on the patient side of the stethoscope, but I have been and again will be on that side. I am not immune. One doesn't have to be a student of the Dharma to know this.

I find an enormous amount of tenderness in recognizing the shared nature of this human reality. A profound and healthy intimacy arises through attention to the unique way that mortality awareness unfolds for each person. It is a practice. You could call it kindness or presence.

The opportunity to engage in reflection with people under these conditions is a powerful experience. I often point out to the dying person that they are only one second ahead of me or their loved ones in millennial time. What can you tell us from that perspective? What are you learning? The last cycle of their life sets an indelible imprint of dying for their loved ones. Death becomes a teaching. This recognition motivates some people to plumb the depths of their humanity during their dying process. There can be wisdom and peace, even as there is dread.

Q. What you are saying is that pain is inevitable, but suffering is optional, depending how you choose to interpret the pain?

A. I don't know that suffering is optional, because I don't know anyone who hasn't suffered, and because suffering is happening all over the world right now. What I am saying, what I believe, is that by learning to turn toward suffering with skill and kindness, well-being is possible. There are practices handed down across

millennia that point toward spiritual vitality. Buddhist practice in its various forms is one of those offerings. It is one way to enter into being fully human, to having what I call 'near-life' experiences.

People have asked me, "Are you a Buddhist?" The clearest response I've come up with is, "I don't know. I am a Buddhist in the same way that someone who plays the piano calls themselves a pianist. As a pianist, you are trying to create music. You are exploring sound in an open-ended way. In meditation practice, you are exploring experience. You are inquiring into things. You are not taking things for granted."

There are many paths to this inquiry other than the great religious and contemplative traditions. "Dharma gates are countless," as they say. Illness can be one of those paths. You find yourself in a circumstance where you are stopped cold. In that limitation, you bump up against your wish for things to be different. When you recognize that this is impossible, the potential for radical awakening, radical acceptance is before you.

This insight is the beginning of inner freedom. You discover that by simply according in a relaxed way with the sensate experience of *itch*, your *itch* suffering diminishes significantly. You are not compelled to act on thoughts about the itch. It is then that you have some freedom. You have some choice.

Death awareness brings undeniable knowledge of human limitation, and with this knowledge, the potential for freedom. You learn that your thoughts about death and death itself are not the same thing. You discover that death has a life cycle of its own and that you can accord with it in a way that brings inner freedom. Death is independent of mental proliferation about it.

The truth is that **nobody escapes limitation**, voluntary or otherwise. Illness, credit card debt, loss of relationships, wrinkles, hunger, flat tires, and tornados create boundary experiences. Limitations arise that you cannot avoid. They sneak up on you unexpectedly. An opening can occur right in the middle of the suffering. The courage to turn toward such circumstances is a practice, and opens a door to a new world. Meditation practice is voluntary limitation and sets the conditions for opening, but you can't control when or if opening will occur. You can practice for years and years and you think nothing is

happening. All of a sudden, something will sneak up and jump all over you: “Wow. I wasn’t even aware of this. How amazing!”

Q. What a compassionate physician you are. It is beautiful to hear how you look at illness in your patients.

A. Well, it’s really a practice for me as well. What Buddhism teaches is inherent in the illness experience without having to be named. That applies to me as a physician, as well as to the person I am working with. The full potential of what it is to be human is right there in the center of illness. It is a matter of focusing in a way that inclines the heart toward wisdom and well-being. It is a way of life.

NW: Thank you for taking the time for such a thoughtful and thought-provoking discussion of the interplay between your understanding of the Dharma and modern medicine. You have offered incredible insights into the compatibility between the two disciplines, which, as we know as students of Buddhism, are not really separate at all.

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Dharma and Illness

by David Zucker, MD, PhD

When we take on a meditation practice, we voluntarily limit ourselves. The outward symbol of this limitation is the practice itself. We commit to coming back, to relaxed alertness, to stillness. We welcome whatever arises. Through this voluntary limitation, through holding whatever arises without adding or subtracting, we become students of the Dharma.

Illness also limits us, but this limitation is involuntary. Generally, we do not like illness because, unlike meditation practice, we cannot abandon it at will. Illness challenges our sense of control, the ability to have things ‘our way.’ It challenges our projects, our goals, our identity. In short, illness challenges what we hold to be our direction life. It lays bare the fact of our vulnerability, fragility, and—in a heartbeat—our mortality. In serious illness, there is little ‘wiggle room.’

Although we cannot control the inevitability of illness in our life, we can take it on. How can this be? How can we ‘take on’ something that we do not choose? This is because illness, like practice, has little to do with the perception of ‘voluntary’ or ‘involuntary,’ although in the beginning it may seem to.

Rather, taking on illness is the commitment to resolving the image of illness into its component parts, to embracing uncertainty, to becoming sensate. Neither illness nor meditation has in the end anything to do with limitation at all. In the moment we take illness to heart a practice, we leave both illness and meditation behind.

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Zen Vocabulary

Bodhichitta	awakened mind, or the wholesome desire for enlightenment.
Bodhisattva	enlightenment being, a being who seeks buddhahood through systematic practice of the perfect virtues.
Buddha	awakened one—a person who has achieved the enlightenment that leads to release from the cycle of existence. Also, Shakyamuni Buddha, the historical Buddha.
Chiden	sangha volunteer who takes care of the altar, cleaning, changing flowers, etc.
Dharma	the cosmic law underlying our world including the law of karmically determined rebirth. Also, the teachings of the Buddha.
Dharma Talk	talk given by priest or teacher about the Buddha's teachings.
Dharma Name	one's Buddhist name, usually two pairs of Chinese or Japanese characters; received from a teacher during Jukai.
Dharma Transmission	the manner in which the teachings or Dharma, is passed from disciple and heir. The procedure establishes the disciple as a transmitting teacher in their own right and successor in an unbroken line of teachers and disciples, a spiritual 'bloodline' (Kechimyaku) theoretically traced back to the Buddha himself. (Haskel, Peter; <i>Letting Go, The story of Zen master Tosui</i> ; University of Hawaii Press).
Doan	the sangha volunteer who rings the bells during service.

Doanryo	(do-an ree-yo). Doan work group, the group of people who ring bells and lead chants during service. See also Doan, Kokyo, and Tenken.
Dokusan	means literally ‘to go alone’, a private interview between student and teacher. See also Practice Discussion.
Ino	the sangha volunteer who is in charge of supervising and leading activities in the meditation hall, training the doanryo, and maintaining the zendo schedule.
Jisha	the sangha volunteer who attends to the teacher: helps with ceremonies, brings people to dokusan and helps the teacher in other ways including arranging travel, housing, and food while the teacher is visiting.
Jukai	literally means ‘receiving the precepts’, a ceremony through which one officially becomes a Buddhist and receives the rakusu—also called lay ordination.
Kinhin	walking meditation, usually done in between periods of sitting meditation, literally ‘sutra-walking’.
Kokyo	a person who leads chants during service.
Mahasattva	great being.
Practice Discussion	private interview with a priest or Dharma leader to discuss one’s practice. Less formal than Dokusan. Available in our sangha with the Resident Priest or senior lay students.
Precepts	guidelines for behavior in daily life, derived from the rules that governed the community of monks and nuns in the time of the Buddha.
Rakusu	symbolic of the Buddha’s robe, a bib-like garment that is conferred on one who has gone through the jukai ceremony. The teacher writes the ordainee’s dharma name on the back.
Sangha	literally, crowd—the Buddhist community. Can refer to members of Red Cedar Zen Community or more widely to all Buddhist practitioners.

Samu	work period conducted mostly in silence with attention to the body and breath and the task at hand.
Soku	sangha volunteer who leads a serving crew (serving tea or a meal formally in the Zendo).
Sōtō Zen	school of Zen founded in Japan (via China) in the first half of the 13th century by Dogen Zenji.
Tathagata	one of the ten titles of the Buddha, literally the 'thus come one' implies 'one who has attained supreme enlightenment'.
Tenken	the sangha volunteer who keeps track of time in the meditation hall.
Zabuton	a square sitting mat used in meditation.
Zafu	a round cushion used in meditation, usually with a zabuton.
Zazen	sitting meditation.
Zen	Japanese word (via China) based on a Sanskrit word meaning 'collectedness of mind or meditative absorption'.
Zendo	meditation hall.

*Blessing on All Sentient Beings
in All the Six Worlds*

