Embrace Tiger, Return to Mountain

Writer JODY WILSON discovers there is nothing like the diagnosis of a potentially terminal illness to focus the mind.

Consciousness is a slippery slope, especially when you’re wired into a heart monitor, wearing an oxygen mask, dealing with a drain inserted in your pleural cavity and arguing with your husband about using the on-demand intravenous morphine drip.

“I’m fine,” I insist inanely, hoping to be heard through the oxygen mask. Translation: “I am terrified that if I use the morphine and go to sleep, I will die. I will die in a drugged stupor, unconscious, without realization. I will die a bad death, without courage or hope. Please don’t let me die that way.”

“You’ve got to get some rest,” Bob replies with the same steely-eyed reasonability he’s been facing me down with for hours. Translation: “You will not die today. Let go with trust. There’s no need to struggle now. You need to sleep so you can live. Please live.”

My sons aren’t constrained to treat me as an equal or take me seriously and if they can hear the subtext, they choose to ignore it. They jam my headphones on my head, crank up “Abbey Road” and take turns hitting the morphine button every 15 minutes. It’s fun to turn Mom on.

It’s less than 24 hours after undergoing a partial left lung lobectomy. The inferior lobe contained a malignant tumor the size of a tangerine. A couple of dodgy looking lymph nodes in the media stenium were also excised and the surgeon was “pretty sure” he got them all. The diagnosis is non-small cell lung cancer, 3-A on the scale of cancer nightmares. The worst is four. The five year
survival rate is 15% — eight out of ten people will die of the disease within five years. But, if I am one of the statistical two that survive, the odds of my dying of any type of cancer come back in line with the general population or 2 in 1000.

I will say right now that I am culpable. I smoked my first cigarette when I was 15 and my last two months before I was diagnosed. I quit nine times, once for 18 months. And I knew I was a first-class risk; in 1980 I had a fast-growing malignant tumor removed from under my left arm. I am responsible for my own actions, not the tobacco companies, and I suffer the consequences. Karma is, inexorably, karma. All of our actions cause suffering, some more than others. Why do people repeatedly act against their own self-interests? How can you/he/she/they drink/smoke/drug/eat/sleep/shop/fill in the blank to excess when all the evidence, especially the evidence of our direct experience, informs us that our behavior is harming ourselves and others? All my ancient twisted karma, stemming from greed, anger and ignorance, arising from body, speech and mind, I now fully repent. No one escapes.

I was not practicing Zen when I was diagnosed. I was, however, an experienced practitioner of the Zen of Reading All the Books about Zen and, I modestly admit, a pretty adept spiritual materialist. I began this practice at age twelve, just a year after Dharma Bums was published. At twenty four I read Be Here Now, and later that decade The Three Pillars of Zen and Zen and the Art of Motorcycle Maintenance. At thirty, I discovered Alan Watts. At forty, Carl Jung and Joseph Campbell.

By 2000, I had visited Milarepa’s cave in Tibet, acquired a leaf from the cutting of “the” Bodhi tree at Wat Pho in Bangkok, and had spent the night at Lumbini. I’d attended a workshop at the Toronto Zen Centre and had returned to that Centre to sit at other times. But the vibes weren’t welcoming and the energy at the Toronto Zen Centre in 1992 was unsettling. I didn’t stay. I had taken teachings from the Dalai Lama; hugged strangers at Unity churches; chanted at the Vedantist Society; “OM-ed” with a number of celebrity lamas and mamas; danced ecstatically at New Moon rituals, attended New Age “healings” and had otherwise been stumbling down The Road to Inner Peace for some time. At fifty three, spiritual seeking had become my life and although I thought I was working hard to find a “place to worship,” as I described it, I’ve come to understand that all my “seeking” was the main obstacle to my finding. But there’s nothing like the diagnosis of a potentially terminal illness to focus the mind. I didn’t know it, but the seeking was pretty much over and the hard work had not yet begun.

On the third morning after surgery, the sun rose and threw its rays into my east facing hospital room. A nurse was with me, silently and patiently untangling the web of cords, tubes and wires from all the various drips, monitors and drains that ensnared me. As the light in the room deepened, every idea I had about religion, every fierce wish for total faith in a personal God, every cherished idea concerning the nature of things and all of my closely reasoned analysis of existence and being, dissolved. An Ojibwa saying quoted by Joko Beck — “Sometimes I go about in pity for myself, and all the while a great wind is bearing me across the sky” — rose like the sun in my newly minted mind. I spoke these words out loud. The nurse turned to me and smiled. “I thought you were asleep,” he said gently. “Not anymore.” He held my hand while I wept. His presence was witness, his silence a balm. The experience was completely full, completely empty. I was discharged the next day, 48 hours before anyone had expected, borne by a great wind across an empty sky.

It’s well documented that people with cancer or other serious illnesses who cultivate and maintain a positive attitude live longer and have a better quality of life than those who don’t. This point of view is pervasive at every level of the experience. All hospital personnel from the head of surgery
Emotions and thoughts are chemical. Negative thoughts weaken us. Positive thoughts and feelings strengthen and heal us. The goal is to “stop every negative thought and action in your environment whether you think it, say it, or are in the field of someone else who says or does something and replace it with a positive thought,” according to one source. “Positive affirmations can shrink tumors,” claims another. “You are the commander of YOUR body! Take charge and command your cells to be healthy. You do not have to accept and enable what’s happening to them. You may command the cells in your body that are here to serve your Soul!”

Hallelujah! I could think my way out of this! I longed to believe that I was essentially in control and had ultimate power over the events that were coming downstream, including the very real possibility of a horrible death from a wasting disease. It would be a dream come true to force this nightmare into something I could manage and control. I wanted to wring it dry of every hint of uncertainty, ambivalence and ambiguity. Who doesn’t yearn for a future that is solid all the way through? Like baloney, no matter where you cut, it is the same, a completely consistent and predictable physical, emotional and mental package. No surprises.

But the Great Matter had whupped me upside the head good and proper. I now knew, without a doubt, that I was not enthroned, solitary and omnipotent, at the center of the universe. If we are ever the “captains of our fates and the masters of our souls” it is only under the most limited conditions — relegated to our selections between pink or blue, whole or skim, Coke or Pepsi. The notion that we have the power to command our cells to heal as if they were a pack of bad dogs is the seductive danger of New Age spirituality. It tempts us with a fantasy of unparalleled personal power, encourages us to use that power for our own self-interest, and ultimately affirms our unalienable right to get our own way. It’s true, isn’t it? What we call “positive” thinking is always in accord with our ego preferences — an abundance of wealth, health and happiness — while “negative” thinking always describes our aversions — financial insecurity, ill health and (the ultimate aversion) — death. That we can know what is ultimately good and ultimately bad and drive our lives towards the good and away from the bad is essentially ego inflation, a fantasy of God-like power. Besides, who really knows what’s good, what’s bad?

In ancient China, there was a poor farmer whose only valuable possession was a horse. One day, the horse ran away. A neighbor rushed over to commiserate. “That’s terrible! What a tragedy, a real misfortune.” The farmer answered, “Who knows what’s good, what’s bad?” The next day, the horse returned, leading a herd of wild horses into his corral. The neighbor hurried over to compliment the farmer on this unexpected windfall and his stunning good luck. “You’re a rich man now! What a great thing for you and your family!” The farmer answered, “Who knows what’s good, what’s bad?” The next day, the farmer’s only son, attempting to tame one of the wild horses, was thrown and broke his leg. The neighbor ran to comfort the farmer. “A disaster, certainly. Who will help you bring in the crops? Terrible!” The farmer answered, “Who knows what’s good, what’s bad?” The next day, the army marched through the village, conscripting all able-bodied youths, but the farmer’s son was not taken because he had a broken leg. So the neighbor...

. . . well, you know the rest.

People with serious illnesses can become prisoners of positivism, captives of the either/or, good/bad, positive/negative, mind states. I knew I didn’t want either/or. I hadn’t for some time. Now I was finding both/and to be unsatisfactory. What I
was discovering was that the imperative is not to be positive, the imperative is to be present.

I was optimistic about the outcome, including — not in spite of — the very real possibility that I would die from this disease within five years. And while it is preferable and pleasant for us and the people around us for to be positive in these circumstances, in the end both Pollyanna and Scrooge are equally crippled.

My optimism was coming from a different place, a knowing that, regardless of my own particular and personal outcome, everything was, is now and will essentially be okay. A few years later under different circumstances, Sensei told me that Roshi Kapleau often said: “Don’t worry. You can’t fall out of the universe.” That is a near perfect expression of the knowing that I experienced. The optimism that sprung from this energy is what enabled me to be present for this experience, not from “positive” thinking.

When I took my Jukai Precepts Ceremony, I wrote:

Bad thought.
Good thought.
Just thought. No thought
Ah!

But that was later. In the six months between diagnosis and the post surgery, post chemotherapy, post radiation benchmark CT scan, my job, as everyone kept reminding me, was to “beat this thing.”

The language of cancer (or any serious illness) is the language of war. We attack cancer and conquer it. We are urged to be strong in the fight against cancer. We are told that early detection is the best defense. There are cancer battle plans, aggressive strategies to kill cancer and an entire library of books with variations on the title, “Fight Cancer and Win.” An individual’s experience with the disease is often described as a “last stand” or “a desperate struggle.” Certain foods and supplements are described as “cancer-fighting;” nutrition, exercise and alternative therapies are “weapons.” There are victims and survivors. Survivors are courageous and brave. Some, like Lance Armstrong, are heroes. Some, like Dana Reeves, are martyrs.

The military vocabulary drove me nuts. I am a dove politically, non-violent socially and non-aggressive by design and desire. But I’m not a pacifist. Even now, as a practicing Buddhist, I will fight to defend others. Under certain circumstances — like this one — I will also fight to defend myself. But how do you fight your own cells? What was there to fight? Maybe the cancer cells that survived the surgeon’s knife (another weapon) were forming a fifth column in my body. Was I harboring the enemy? Or was I the enemy? Who fights? Who lives? Who dies? Now I see these questions as the seeds of koan practice. I was angry, disturbed and completely flummoxed (which, now that I think about it, was also my initial response to formal koan practice.)

My resistance ran so deep that I did something completely out of character. I dropped the struggle and shut up. I nodded and smiled. I learned to tune out the clichés and listen to my own heart and mind. When I did, I understood one simple fact. The ground is falling away under our feet — ALL of our feet, ALL of the ground, ALL of the time. This was the only thing I was sure of as I embarked on a 28-day cycle of radiation therapy and one course (two cycles, administered through six infusions) of a chemotherapy blend of Taxol and carboplatin or TaxolCarbo.

Taxol is, basically, a natural botanical, an extract from the bark of the Pacific yew tree (Taxus brevifolia). The problem with using natural Taxol as an anti-cancer treatment is that it is unconscionable
environmentally and off the charts in terms of cost: it takes between three and ten 100-year-old trees to treat just one patient. But luckily the needles and twigs of the European yew tree (Taxus Baccata) were found to contain a close relative to Taxol. As the trees quickly replenish the needles, harvesting large quantities has little effect on the population of yew trees. A semi-synthetic version of Taxol, Paclitaxel, was introduced in 1995. Still wildly expensive, of course, but sustainable and relatively practical.

I was inconsolable, my feelings of despair beyond words of comfort or reason. The next day, my husband shaved his head.

An infusion of a semi-synthetic botanical, like a rare medicinal tea, perhaps, or a complex herbal cocktail, that doesn’t sound so bad, right? In fact, I was feeling pretty good about it, despite the short list of side effects — hair loss, loss of appetite, nausea, painful bones and muscles, numbness and tingling of limbs were the manageable minimum to expect. More serious things like internal bleeding, respiratory and/or gastrointestinal problems, mouth sores, fever and bone marrow depression were distinct possibilities.

The most fearsome item on this list of horrors is hair loss. Trust me. No woman who has ever faced chemotherapy will tell you otherwise. Remember the classic Jack Benny routine? Benny is held up at gunpoint. The robber says, “Your money or your life.” Long and delicious pause. The robber repeats his demand. Benny says, “I’m thinking, I’m thinking.”

“Your hair or your life,” says the oncologist, metaphorically. And one hesitates! The idea that I would lose my hair — which, frankly, I never liked anyway, it being always thin and limp and full of cowlicks — opened a floodgate. My tantrum was worthy of any two-year-old. There was nothing to say.

There are essential differences between pain and suffering. Pain is unavoidable — suffering is optional. Pain is what happens. Suffering is the story we tell ourselves about what’s happening. Or has happened. Or might happen. Pain is physical. Suffering is mental. In the chemotherapy room of the Strauss Oncology Center at Weiss Hospital the already thin wall separating physical pain from mental suffering is permeable to the point of transparency. (And a mighty cheerful place it was, too.)

Forbearance is an old virtue that has a bad rap. Often linked with patience, forbearance is a level or two deeper. Patience is something one exercises while in line at the supermarket or in traffic. Forbearance is more like a willingness to absorb pain with as much good humor, courtesy and self-lessness as one can muster. In fact, one of its dictionary definitions is “long-suffering.” The practice of forbearance is what made the experience of willingly poisoning oneself at regular intervals bearable, even enjoyable. Without exception, every single person I encountered was cheerful, helpful, hopeful, open-hearted and brave. It was a privilege to be there. I learned how to sit for hours in the presence of others on the same journey; uncomfortably pinioned to an intravenous drip, experiencing the benefits of stillness one moment, resistance to it the next, breathing through it all, trying not to watch the clock and struggling to be with what is. I often flash on this experience in the few moments after a formal round of sitting in the zendo when we all rise for kinhin, slow walking meditation.
While chemotherapy had a group energy, radiation was a solitary experience. Perhaps because of that and because it meant a daily trip to the hospital, the worst of the two. It was here that I think I first faced the First Noble Truth. “Suffering, or unsatisfactoriness, is a condition of existence.” Not just my existence. It is neutral. If we take it personally, we’re doomed.

In January, 2001, I became a Buddhist. It happened during a regular appointment with the oncologist following the “benchmark” CT scan:

“There is a mass on your left lung. It’s probably scar tissue, completely consistent with your experience.”
“What?!”
“There is a mass on your left lung. We’re pretty sure it’s scar tissue.”
“Pretty sure?! What does that mean?”
“Scar tissue looks like a mass on these scans.”
“My tumor looked like a mass on the scan.”
“Right.”
“RIGHT????!!”
“Right.”
“How do we know it’s not a tumor?”
“We compare scans. If the mass is larger next time, it’s probably a tumor. If it’s the same it’s probably scar tissue.”
“You’re kidding, right?”
“No, I’m not kidding. The mass could be either a tumor or scar tissue. We’re pretty sure it’s scar tissue.”
“When will we be certain?”
“Never.”

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