

Giving Up the Fight

By Rebecca Stanfel

It was my 47th day as an inpatient in the hospital.

My mom was talking to me. I didn't feel like talking. Or listening. I was in pain, so much of it that I was hooked up to a pump administering a powerful narcotic called Dilaudid. I pulled away from my mother's words, from the strips of sunlight leaking through the blinds, and focused on the rough touch of the hospital pillowcase against my cheek, the plastic pillow crackling underneath the cloth.

"You have to fight," my mother said. "You have to beat this."

I made a sound without syllables to signal my assent. In pain, words were hard to hear, harder to produce.

"You have to fight for your family," she said. "Andrew needs you. He needs his mommy."

My mother squeezed my shin under the blanket. Then I felt her fingers wiping away tears I hadn't known were on my cheeks.

"I know, Mom, I know," I said. "I will." And I tried to find the fight in my battle-weary body.

That 47th day of 80 was during the first of five hospitalizations, each lasting for months at a time. In between them, I was often bedridden at home. My illness is sarcoidosis—a rare, potentially chronic, and fatal inflammatory disease. I was diagnosed when I was 33 when Andrew was three months old. For 19 years, the illness has spread around my body, causing severe neurological and cardiac issues.

I spent over a decade doing as my mother and countless others told me to do. I *fought* my illness. I fought because what I feared the most was that I wouldn't live long enough for my son to remember me. I fought when a cardiologist told me I "could drop dead at any moment." Andrew was two. I fought when another doctor told me I wouldn't live to see him graduate from high school. Andrew was eight. He's now a freshman in college. I'm still alive.

For many years, I could think about my sarcoidosis only as war. Of winning or losing. It was me against sarcoidosis. We were locked in brutal trench warfare—each dug in behind barbed wire. Only one of us would win. It had to be me. I could not lose. I was fighting for my son. Fighting for my life.

I didn't invent this idea that to live with an illness; I had to fight it. These metaphors of war came, unbidden, from the silent depths of my unconscious, from those who loved me, and from the world around me. Fighting (or any of a number of synonyms) is how we—both patients and our broader society— choose to understand and speak about illness. Read nearly any obituary for someone who died of an illness. They "fought hard" (or "valiantly," "courageously," or "bravely") and then they "lost their battle" with the disease. Whether it's cancer or COVID-19, Parkinson's or sarcoidosis, ALS, or COPD, we all fight. And if we die, we lose.

If you're a patient, this language is everywhere. The Cancer Treatment Center where I went for infusions for my sarcoidosis had posters about not giving up "the fight." Other patients wore t-shirts that said "I'm Kicking Cancer's Ass." My family and friends, the nurses who treated me, all told me that I was a warrior. My therapist, a white-haired, New-Agey woman who had previously taught me techniques to relax my breathing and engage with my inner child, also shared how she'd approached her own cancer and chemotherapy. She told me to visualize each drop of chemotherapy as a nuclear warhead targeting my body's rogue inflammatory cells. I dutifully visualized.

This idea of fighting imbued my daily life, not just chemo treatments and hospital stays. I saw my life as battle to battle. It was a win if I got out of bed, a loss if I didn't. Drawing or playing Legos with Andrew—victories. Showing up at his school for a play. Sitting at the dinner table with Andrew and Jay, my husband, —more righteous victories. But the days when the pain slammed me back into bed, or when the vertigo was so severe I fell over when I tried to get up—losses. When I couldn't make it down the stairs for dinner, I would lie silently above Jay and Andrew, listening to their chatter. I hated myself thoroughly. I was ashamed. *Such a wimp. Such a loser.*

Like so many patients with chronic illness, I saw these daily battles as part of a much bigger fight. I thought I would get my old life back if I won the war. I'd return to work, driving, grocery shopping, cooking. I'd be the partner to Jay and the mother to Andrew I wanted to be, expected myself to be. If I could bareknuckle my way to somehow hear the magic words of "remission," I would win the war for my life. I would live. The universe would pin a medal of bravery on me.

Dug deep in my trench, I could not see the physical and emotional damage this thinking caused me. In my quest never to concede an inch to sarcoidosis, I broke myself down. I was exhausted. Pushing myself constantly made my pain worse, my vertigo unbearable, my heart issues requiring shocks from my defibrillator. I made myself sicker, more exhausted.

It hit me one day in the cancer center, watching chemotherapy drip into me. After more than a decade, I was at best in a stalemate in this forever war. I took handfuls of pills every night and

spent entire days every month getting infusions, which usually left me feeling sicker than when I'd arrived. Months in the hospital. More in bed. I was not winning. In the haze of the Benadryl that I got along with each infusion, I realized that the rogue cells were *me*.

I was the earth into which soldiers dug their trenches. I was the sky from which planes dropped bombs. I was the jungle defoliated by Agent Orange. I was the wedding party vaporized in a silent drone attack. I was the field of battle. I was both victim and aggressor. Broken and beaten. Nothing was fixed. And still the paratroopers kept landing.

I am certainly not the first person to realize how damaging the ways we think of illness can be. In 1978 Susan Sontag took up this question in her masterpiece, *Illness as a Metaphor*. Sontag had her own first-hand insight—she was undergoing treatment for breast cancer when she wrote this work of critical theory. She didn't focus on the metaphors of war that we use to think of illness. Instead, she took issue with *all* metaphors of illness.

Sontag thought that metaphorical frameworks for illness end up blaming the patient for being sick. Whether it was medieval Christians who believed that sin explained sickness, 19th-century doctors who thought fatal illnesses like tuberculosis reflected some lack of inner “character,” or some of her own contemporary psychoanalysts who posited that repressed emotions caused human illness, Sontag saw this symbolic language silencing and shaming patients. She believed we had to let them all go. On the first page of her treatise, she wrote, “The most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking.”

Reading Sontag didn't instantly snap me out of thinking of my illness as a war. This worldview was around me everywhere, and everywhere inside me. Perhaps our society turns to the language of war when we want to signify something with the highest stakes. Just in the last 40 years, American Presidents have launched wars on poverty, cancer, and, of course, drugs.

What has higher stakes than wanting to live to see your child grow? To live to be with your partner?

Other theorists have criticized Sontag—from academics to journalists. In her article “Who's Afraid of Susan Sontag?” Barbara Clow argues it is “impossible to strip illness of its symbolic meanings.”

Linguists have also explored the role metaphors play. For example, in his 1980 book, *Metaphors We Live By*, George Lakoff proposed that metaphors aren't merely figures of speech, as we are taught in fourth grade. Instead, they are tools that connect physical and social realities to abstractions. They allow us to think abstractly. Metaphors not only have the power to shape the way we think. They *are* the way we think.

I am no philosopher or linguist. I am only a woman who has lived with an illness for nearly 20 years.

Perhaps, if Barbara Clow and the linguists are correct and we need metaphors to understand the abstract horror of illness, some bright mind can think of a better metaphor. One that does not turn our bodies into killing fields and imply we are losers if we sicken. Or die.

I still wrangle with how to think and talk about my illness. I try not to say, "I'm fighting sarcoidosis." Instead, I say, "I am living *with* sarcoidosis." I try and believe this too.

I have a better quality of life if I don't think of my illness as my enemy. It's not that I've "accepted" it and don't wish it would go away. But sarcoidosis seems pretty intent on sticking around. I understand that it is my own immune cells causing my problems. If there is an enemy, then it is also me.

We are a species that looks for patterns. Correlation is not causation, and yet it feels so. Perhaps that's why we've deployed various strategies to contend with illness for millennia—from God's punishment to New Age "healers" who blame illness on repressed emotions to "clean" eaters who think turning down a cookie will prevent cancer. They all want to address that aching human quest for patterns and meaning. They all want to answer the "Why?" that we scream inside when we or someone we know gets sick.

All of us long for control. We use language to cordon off and contain the reality that we are mortal creatures always at risk of illness and death. War is hell, but it's there to be won or lost, if only we try harder, get more bombs, annihilate more faceless enemies.

It is terrifying to let go of notions of control. I certainly didn't want to. Surely my excellent diet and hours in the gym would banish illness. I ate my five servings of fruits and vegetables. I couldn't possibly get cancer. Or get some weird disease I couldn't even pronounce. And when I did, I told myself I had the willpower and the stamina to fight my way through it. I could control this.

But I have no control. Or very little. Unfortunately, you do not either.

That is why for now, I've settled on this uneasy terrain of conceptualizing "living" with my illness. We share a body. The illness is my body. I often still push myself too hard and set myself back. But I am beginning to be able to listen to the sarcoidosis. I am beginning to stop hating myself when I listen. As much as I want to go for a walk—and as much as I believe I should be able to go for a walk because I got 12 hours of sleep, ate a good breakfast, and swallowed all my medications—there are days when I understand the choice is not mine. I retreat to the couch. I hope tomorrow allows for a walk. More often than not, it does because I am not breaking my body and spirit down, fighting every inch every day.

Is my sarcoidosis like a difficult roommate? We share space, and no matter how much I complain, she leaves dirty dishes in the sink and eats my peanut butter without my permission. Or perhaps I am a manager, and my sarcoidosis is a problematic employee, someone I can't fire because she has key operational duties. But she is also unreliable and too often doesn't turn up for work.

There I go again, looking for metaphors, trying to build conceptual walls around reality. It's hard not to.

I am trying to grasp the bigger picture. Control I abdicate now by listening to what my body tells me means the possibility of doing more later.

Ironically, the less I fight, the more I can do in the long term. It's like the computer's epiphany in the 80s classic movie, *War Games*: "It's a strange game," it says about nuclear war. "The only winning move is not to play."

Leaving aside productivity, I am less crazy feeling. Less bitter. Happier. Less angry at myself. At times I even feel genuine empathy for myself.

This empathy grows outward. Now when I read an obituary in my local paper, I skim over the language of "battles" or "fights." I try to hold those who died in my mind, to honor them and all the chaotic and random variables that brought them into being and then took them out. I don't want to think of these people as losers in a battle. I don't want to imagine them fighting in their last minutes. They lived, then they lived with a disease, and then they died. And so shall we all.

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