

# Illness as Muse

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It is not unusual, after I've given a poetry reading, for some impossibly young writer from the audience to remark over the post-literary pretzels and Diet Coke, "Wow, your stuff is really depressing." One especially unkind reviewer of my books proclaimed—in a similar but perhaps more impatiently dire vein—"Bad things happen in Rafael Campo's poems." Coming from a fellow poet—and none of us are generally associated with boundless joy, or even middling cheerfulness—his indictment seemed inordinately cruel. Even my devoted spouse counsels me, after reading my latest villanelle about botulism or ode to schizophrenia, "Honey, maybe you should think about lightening things up a bit." Try as I might to take all of this concern to heart, to see butterflies or snowflakes or flowers as more suitable, or at least less foreboding, objects of literary address, I keep finding myself drawn to write about illness.

Like anyone, I despise the kind of person who slows down his car at the sight of a roadside accident, craning his neck in the hopes of glimpsing some awful carnage. I hate television shows like *House* and *Grey's Anatomy* for making a ludicrous spectacle of illness. I can't stand it when innocent family members solicit advice about their hypertension or cholesterol, because it seems to me there is so much in the world that is more interesting to discuss; I grew impatient even with my endearing grandmother, when she was still alive and would ask me my advice about her blood sugar.

When I feel I'm about to fall ill myself from such constant noxious exposures, I dig out my well-worn copy of Susan Sontag's scathingly sober *Illness as Metaphor*. "My point is that illness is *not* a metaphor, and the most truthful way of regarding illness—and the healthiest way of being ill—is the one most purified of, most resistant to, metaphoric thinking," Sontag says, and I think "Take

*that*, Sharon Olds!” “The romantic view is that illness exacerbates consciousness,” she goes on to say, and I crow, “Take *that*, Franz Wright!” What a relief it is to understand illness for what it really is—matter-of-fact pathophysiology; a boring, unpleasant and decidedly non-revelatory experience. Illness is a problem for the human imagination only insofar as we might seek dispassionately scientific methods to cure it while we avoid the inevitably destructive pressures it exerts on our fragile psyches.

Of course, the next morning always comes and I find myself in my clinic again, the exam room speaking aloud in all of its blatant metaphors—the huge clock above where my patients sit implacably measuring lifetimes; the space itself narrow and compressed as a sonnet—and immediately I’m back to thinking about writing. Soon enough, my patients start to arrive, and the way they want me to understand what they are feeling only immerses me more deeply in language’s compelling alchemy: “The pain is like a cold, bitter wind blowing through my womb,” murmurs a young infertile woman from Guatemala with what I have diagnosed much less eloquently as chronic pelvic pain. “Please, doctor, can you heal me?” I regard her from across the desk, and feel grateful for the computer terminal more immediately in front of me, which allows me to type a little medical jargon into my note before having to actually speak to her. “Send her for an exploratory laparoscopy,” growls Susan Sontag in the back of my mind, but she’s already had that procedure, along with several ultrasounds and pap smears, innumerable blood and urine tests, a hysterosalpingogram, a colonoscopy, and a trial (ironically) of birth control pills. We have had this conversation before, which I realize is another way of saying we are together part of a narrative, a story. A story in which irony matters, in which understanding metaphor—might her pain be a wordless expression of her deep sadness at her inability to have a child, or perhaps the consequence of some trauma she has not disclosed?—seems to have some irrefutable value. Now, I am thinking again about writing, but not a prescription for the pain medication she always refuses; instead, I am thinking about writing

a poem like Sharon Olds. I am thinking about the metal speculum clattering in the sink while she sobbed softly after I performed her last pap smear, as if it were trying to reiterate something about coldness and bitterness, or what we hear and can’t hear, or pain and abjection.

Perhaps something about this young woman reminds me of my grandmother, herself an incurable—and incurably hopeful—immigrant, which only amplifies my narrative impulse. After all, it was my grandmother who first inspired in me a love of stories. Her words were all she could give me of our homeland, Cuba, that exotic and forbidden place, her own unspeakably painful void. My grandmother was afflicted with what seemed an unfair burden of illnesses. Her treatments for her ailments seemed just as varied as the ailments themselves, from the pills she dutifully swallowed each morning—some prescribed to her by doctors, some dispensed out of her friends’ personal hoards—to the prayers she recited before her own tiny shrine to the Virgin Mary; from the magical, strange-smelling *potajes* she brewed with roots and herbs that can’t be found in American supermarkets, to the sheer will to endure that seemed manifest in her meticulously kept apartment and her constant humming to herself of old Cuban songs. Some of her illnesses were familiar ones, like diabetes and rheumatoid arthritis; others were conditions that were utterly untranslatable from Spanish to English, like the terrible *patatú*, some kind of debilitating nervous attack, or the more insidious but equally awful *retortero*, which could afflict her for weeks, or even months.

Through her experiences, I saw firsthand just how indistinct could be the boundary between the tersely biomedical and the wildly superstitious: she took gold for her painful joints that the rheumatologist prescribed, the same doctor who ridiculed her use of traditional Cuban remedies. As an impressionable child, I marveled at the idea of this precious metal somehow gilding my grandmother from within, protecting her joints from damage by the power of our wonder at it. Decades later, when she finally died of kidney failure induced by the toxicity of what proved to be a

worthless treatment for her, I learned the meaning of irony for the first time. If her rheumatologist in his starched white coat could have been so wrong about one form of treatment, maybe he was just as mistaken about the mystical powers of what was prescribed by the *curanderos*, whom he regarded as ignorant savages.

Maybe Sontag's premise that illness is mere pathophysiology, to be explicated only biomedically, is not an entirely correct notion either; perhaps illness is a kind of muse, luring us to acts of the imagination and gestures of language that have positive effects on our hearts and minds. Song delighted my grandmother, and prayer consoled her; her joints seemed to move freely again when she danced a merengue, or when she knelt her large form before *la virgencita*. No wonder I have come to believe in the power of the imagination if not to cure, then to heal.

Yet still I resist the urge to write. I scold myself for my prurience. I fret about whether I might be too glib or too sentimental. I agonize over my stake in the telling. Illness may be a muse, but it is a particularly vexing one. I suppose at the root of any act of narrative lies some inchoate desire to bear witness, to say "I was there," to join with others in a signal experience. When that signal experience is illness, this empathetic impulse seems all the more overpowering, as if some deep survival instinct were triggered, as if we might share in the discovery of some profound knowledge we need to live. If the sensational can thus give way to wisdom—even as we are shocked, we are at the same time comforted—so too can sentiment be supplanted by genuine emotion. Surely we must feel moved by the plight of illness, lest we fall into one of the very traps of specious narrative that Sontag bemoans—when illness strikes, it is not because we are guilty or deserve it, and our defenselessness stirs in us the compassion we feel for the innocent, the underdog, the fighter. How much I want to help my Guatemalan patient; how acutely did I wish I could alleviate my grandmother's pain! When I write about them now, I recall the joke in my heavily seasoned Latino-Italian family that if you're not screaming or crying when you say something then you don't really mean it, so I must defeat

my inborn tendency to exaggerate or to pity, but still I must write, in order to restore, to make sense, to heal.

And to be restored and healed myself—yes, I must also admit my complicity in these stories, that I cannot subtract myself completely from them. Sometimes I discover that I'm really writing about myself, my own arrogance or vulnerability or alienation, and I wonder if what feels like selfishness is at the same time an expression of the familiar wish to identify with another person, to affirm that I'm no different, that I'm equally as flawed and conflicted and needy as any of us is. Illness is, after all, one of the few truly universal human experiences; to write in response to it necessarily demands active participation, not the kind of objective, soulless distancing so many doctors practice, and teach their trainees to practice. To write about illness, to heed this terrible muse, is to reject distancing and to embrace empathy, for which there is no reward or claim on greatness other than perhaps the perverse joy of recognizing oneself as susceptible to the same foibles and neuroses.

To write explicitly about one's own illnesses risks an even worse self-indulgence—bunion surgery and hemorrhoids, no matter how distressing to the otherwise healthy poet, simply cannot make for scintillating verse. On the other hand, to write about another's suffering can seem entirely presumptuous, as if it were somehow possible to re-create on the expanse of the clean, neat white page the image an anorexic teenager sees of herself in her bathroom mirror that leads her to induce vomiting—or worse, that somehow, in the earnest imaginative quest for that universal balm that heals, anorexia becomes indistinguishable from anemia, AIDS and ALS and AML interchangeable.

While it's true that the screams of pain coming from the room in the ER where a woman is losing her baby are no more or less heart-wrenching than those from the woman in the next room who is withdrawing from heroin, the specific details of each story must matter just as much as the ultimately indescribable agony they share. "We do not know our own souls, let alone the souls

of others,” declared Virginia Woolf, in her indelibly humane essay “On Being Ill”; though she brilliantly defended the notion of illness as a motive for writing, she too was forced to consider our myriad limitations as our own bodies’ reporters. Yet we must rely on these faulty accounts, perhaps taking additional solace in their imperfections, because to do without them would be injurious to the soul, and to not forgive them would leave us utterly hopeless.

The true cynic who exceeds Sontag in her disdain for our silly superstitions and inane hopes will complain that, regardless of who gets to tell the story of illness, the patient still feels like crap and wants to be either cured or healed, whichever will bring relief soonest and, in these days of limited resources, for the cheapest price. Meaning for him equals results, plain and simple. Illness isn’t a fanciful narrative to him, nor is it the intellectual intrigue of biology gone awry. It is merely some skilled technician’s job to fix before moving on to the next illness, a transaction about which no one need care, an occasion for money to change hands for services rendered as efficiently as possible. Stendahl and Sontag, Olds and Woolf mean next to nothing to him—and even less so as the surgeon stands poised to make his first cut, or as the oncologist starts the chemotherapy drip. He refuses to consider that even in the immediacy of some critical therapeutic act, he is hemorrhaging his unspoken words. By summarily stapling shut his figurative wounds, he is compromising his best chance at survival by denying himself access to all the possible modalities by which the physician might intervene.

His is an expression, perhaps, of the same overconfidence in the scientific model of illness that Sontag glorified. While Sontag was right to denounce the negative metaphors we concoct out of the same ingredients my grandmother used in her more humane and optimistic responses to her illnesses—thanks to Sontag, as well as to other writers she might have disparaged, like Sharon Olds and Franz Wright (or Mark Doty and Lucia Perillo, or Marilyn Hacker and Audre Lorde, or Alicia Ostriker and Adrienne Rich), we simply can no longer view illnesses like cancer and AIDS as being caused

by our fears and our anxieties—we just as adamantly must reject a conception of illness that relies entirely on biomedical definitions.

I am reminded of one of my residents, who was called to run a code on a patient of hers in the hospital just as she was about to leave for the day and enjoy some time with her young family at home. She had followed all the biomedical protocols and algorithms perfectly, barking orders to the nurses and interns with all the confidence she could muster; however, like most end-of-life interventions in the hospital, this one too proved futile, and the patient died. It was only weeks later, when she had the chance to write about the experience (in a poem she created for a reflective writing group that is now part of the residency curriculum in our hospital) did she feel she could do justice to the entire experience, aspects of which she purposefully had shut out at the bedside in the perceived acuity of the situation. Perhaps most salient of all that she had sacrificed to the biomedical exigencies of the moment was the tuning out of the family who were present in the room; she wished she hadn’t ignored them, but instead had allowed them to stop her before a full thirty minutes had passed, when it was already amply clear to them that their mother was dead.

It is precisely situations like these that have so long been cited by medical educators as a primary reason for teaching distancing to medical trainees: to be able to function in an emergency, one cannot regard that patient as a whole person, but rather must focus on the malignant arrhythmia or the life-threatening electrolyte imbalance in order to implement the appropriate technologies and in turn save life at all cost. Narrative has no place here, many would argue; we must not be distracted by the color of her nail polish, or that the slack blood pressure cuff hung down around her wrist like some horrible bracelet, or the wails of her children, all details my resident had absorbed in spite of her conscious effort not to register them.

Yet, if we begin to enlarge the context, as narrative asks that we do, if we start to consider that our actions have impact on others who have their own relationship with the person we see exclusively

as “a patient” (and not as “a mother,” as her children do; not as “a suffering soul,” as the chaplain does), we might act differently. We might move to comfort the patient and to protect her dignity in her last minutes on earth; we might seek to console her children as they face a tremendous loss; we might pray together with the chaplain in the hopes that she not die without the last rites that are soul-saving in many religious traditions. Whether storytelling has a place here is worth considering very deeply; it certainly proved indispensable after the fact, and the poem written by the resident, who failed to resuscitate her patient in the hospital, perhaps has done her an even greater service, by immortalizing her.

None of us lives forever. Many of us might have our lives prolonged by biomedical interventions whose financial costs are exorbitant; too infrequently do we question the toll they also exact on our humanity. The fantasies about what causes illness that Sontag railed against (cancer results from repressed anger, AIDS is a punishment from God) have been replaced by even more deluded fantasies that science somehow can prevent death. The only way we can defy our own mortality is through acts of the imagination, by creating the stories and sculptures and paintings and poems that will outlast us, but that will always be animated by our will to have created them. Even our greatest scientific discoveries can be understood in this way: they are not truly ends in themselves, by which we can ever hope to explicate away our suffering, but are rather part of the same process of dreaming and desiring, wishing and wondering.

When I visited my grandmother in the hospital in the last weeks before she died, I cried for a while into her shoulder. But by then I was a young doctor, so soon I headed for the nurses’ station and pored over her hospital chart while she lay propped up in her bed, the glass and metal ICU like the internal workings of some incomprehensible machine designed for time travel. Countless hours and hundreds of thousands of dollars had gone into the attempt to transform me from a long-term financial burden on my parents to someone with a respectable, moneymaking career. She

was in heart failure despite being on dialysis, and I tried desperately to understand her fluid imbalances. Her I’s and O’s were dutifully tabulated, in a sequence that suggested a code whose rules I might decipher. In my exasperation, I looked up from the record of her gradual demise, and caught a glimpse of her as she fingered her rosary, praying to herself with a peaceful smile on her face, taking her own measure of her receding life. When I write about her now, all the data that seemed so important then have faded to insignificance—but it is that one cherished detail in my memory, this one little story, that always makes her come alive to me again. »