

## An Anatomy of Illness

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**Abstract** Because it focuses primarily on the sick body (disease), medicine ignores many of the concerns and needs of sick people. By listening to the stories of patients in the clinic, on the Internet, and in published book form, health care providers could gain a better understanding of the impact of disease on the person (illness), what it means to patients over and above their physical symptoms and what they might require over and above surgery or chemotherapy. Only by familiarizing themselves with the entire emotional landscape of illness, which includes fear, anger, shame, guilt, and above all loneliness, can the healthy—medicine as well as society in general—hope to heal in a comprehensive manner.

**Keywords** Disease versus illness · Existential symptoms · Alienation · Fear · Shame · Loneliness

Illness has impressive reach.

It begins in the body, with symptoms like fever, weakness, pain. Or in abnormalities detected on a doctor's examination (a heart murmur, a change in mental status) or on a medical test (a high white cell blood count, an abnormal chest x-ray). These signs alert us of trouble within. Something is wrong with my mind, my bone marrow, my lungs.

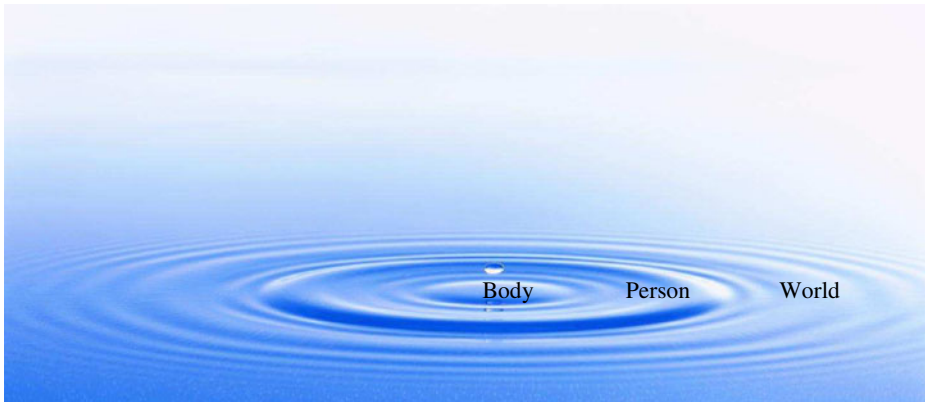
But unlike disease, illness doesn't end in the body but quickly spreads beyond it, fanning outward to involve first the person as a whole—something is wrong with *me*—and then one's relationship to the world—I am now different from *everyone else*.

The reach of illness can be represented by a series of enlarging, concentric circles set in motion by a source—disease—that keeps on repeating itself. From the body to the person to the person's standing in the world and back again.

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Each circle is characterized by a single felt quality: alienation. Something in *my body* doesn't feel right, *I* don't feel right, I don't feel like *other people*. This expanding sense of alienation gives rise to the constellation of feelings that make up the emotional landscape of illness: fear, anger, vulnerability, helplessness, shame, guilt, jealousy, and above all, isolation and loneliness.

Listening closely to the stories of patients in the clinic, on the Internet and in published book form, one finds that all patients, regardless of their diagnosis, will experience these feelings to some degree.

### Estranged body

Illness begins in the cells that make up the body's organs and connective tissue. In the case of Sam DiPietro, the 32 year old manager of a trendy Italian restaurant in midtown Manhattan, a mutation occurred in the DNA of his white blood cells.<sup>1</sup> The mutation led to a malignant clone which proliferated in his bone marrow. Eventually, the abnormal cells outnumbered and crowded out the normal ones. There were fewer healthy white cells to fight infections, fewer healthy red cells to provide oxygen, and fewer healthy platelets to prevent bleeding.

Sam became aware of these deficiencies only when the number of normal cells reached critically low levels. At that point, he kept getting colds that lasted longer than usual. He became tired and lethargic. He bruised when his arm brushed against a hard surface. These symptoms brought him to the doctor and eventually led to the diagnosis of leukemia. They also led to a radical shift in perspective. Previously, Sam didn't give much thought to his body; it simply performed at will, allowing him to work crazy New York hours and still somehow manage to enjoy life with his family. Now he could hardly think of anything else. Why am I getting so tired in the middle of my shift, he asked himself? Why can't I catch my breath chasing after Paul (his 4-month-old son)? His body wasn't letting him do the things that he normally could do.

Illness forces us to acknowledge our bodies and our dependency on them. A compromised body limits our activities. In Sam's case, the limitations were relatively mild. He could still work (though not as much as he might like) and make love to his wife.

<sup>1</sup> The names of the patients, who have generously confided their stories to me, and now to you, have been changed.

However, many patients with more advanced cancers, in the midst of aggressive treatments, or those with severe chronic illnesses like rheumatoid arthritis and lupus, are much more debilitated. They may not be able to work, may at times be confined to a bed. But even if there are no limitations, when, for example, a diagnosis comes unexpectedly after a routine chest x-ray reveals a mass in the lungs, there is always the *fear* of limitations. Illness possesses the potential to render us inactive and passive. It can instantly switch our preferred position from the normal vertical to the dreaded horizontal, as it did for the tuberculosis patients in Thomas Mann's *The Magic Mountain*, and which may remind us of that state of permanent inactivity and horizontality: death (1952, 164).

The body also becomes difficult to control. In the past, there might have been a speck of blood when Sam brushed his teeth in the morning. But it would quickly dry. Now there are times when the bleeding won't stop after several minutes of applying pressure. This terrified him. What if he kept on bleeding and, more terrifying still, what if the bleeding occurred in a more sensitive area like his brain? Sam was also scared when he couldn't increase his energy level by taking short naps and drinking more coffee; if he couldn't keep up at work, he might lose his job. Patients aren't used to losing control over their bodies. Ordinarily we tell our bowels and bladder when to hold on and when to let go. We tell our hands and feet what to do. We say whatever we want to say. Illness changes that. The patient with prostate disease wets himself, the patient with rheumatoid arthritis can't extend her contracted fingers, the patient with Tourette's blurts out obscenities. Like Sam, these patients are scared when this happens and scared too about what might happen in the future. The problem could get worse.

Christine Miserandino, a young woman with lupus who now hosts a patient advocacy website, was amazed at how clueless even the people closest to her were about what it's like to be ill—in particular, the devastating realization that you're no longer master of your own body. The ability to perform the most trivial tasks like getting out of bed or making breakfast cannot be taken for granted. One day while eating with a friend at the local diner, she came upon a clever way to make others understand. She counted out a number of spoons and handed them over to her healthy friend. When you're sick, she explained, you have only a fixed amount of energy, so you have to make choices. Every task costs you a spoon and when you run out, you're done for the day. Done. The friend, at first intrigued by the pretend game, quickly became exasperated—she had run out of spoons before she could take her kids to school in the morning:

When she jumped right into getting ready for work, I cut her off and took away a spoon. I practically jumped down her throat. I said, "No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, then you have to make yourself something to eat before you can do anything else."

The more angry, frustrated and afraid the friend became, the more Miserandino was convinced that she had conveyed an important part of illness, that things are being taken away from you and you can't do anything to stop it.

Uncooperative, uncontrollable, the body also becomes a source of shame. Ordinarily we don't mind sharing the positive features of our bodies that make us attractive to others: our distinctive eyes, our carefully styled hair, the physique we've worked hard to achieve at the gym. But we certainly don't want to share every aspect of the body. Illness doesn't always give us that choice. It can disfigure the body and call attention to parts or functions that we'd much rather conceal. Again, there is a spectrum. Sam is embarrassed by the bruises on his arms and his loss of weight and muscle tone. Though still an imposing man at well over

six feet, he feels much smaller these days, no longer the invincible athlete he used to be. But the shame of illness could be much worse.

John Donnelly is a patient with Crohn's disease about the same age as Sam. When the condition flares, he can't always control his bowel movements. This would be hard for anyone, but especially for a person who prides himself on being well-dressed and well-groomed. At the end of a typical day, John's shirt still looked like it had just come from the dry cleaners, every strand of hair still remained in perfect position. The smell of incontinence drove him crazy. He compensated by dousing himself with cologne, which only drew more attention to the problem. A brief stint with a colostomy bag humiliated him further, and he became clinically depressed.

Laura Denning found out the lump in her right breast was cancerous soon after the birth of her first child, Ruby. It was a shock on many levels. She had always considered her breasts her most attractive feature. Now one would be removed, maybe both, depending on the results of genetic testing. She couldn't stop thinking how it would be when she looked in the mirror, what her husband would feel when they were in bed together, and most shameful of all, whether she would be able to nourish her baby. Just the thought that Ruby would be deprived of breast milk made her sick to her stomach.

Illness by its very nature alienates us from our bodies. A part of the body has become abnormal and compromises the integrity of the whole. My leg hurts and won't allow me to walk normally; the tumor in my breast is disfiguring my torso; the bad cells in my marrow are crowding out the good ones. As Freud once suggested when he spoke of "narcissistic cathexis" in the context of pain, there may be an instinctive tendency to feel sorry for the damaged body part (1959, 171). We cradle the broken arm or pity the breast for what cancer is doing to it. But more often, we start to distance ourselves from the diseased part. We become angry at the leg for not withstanding the blow, at the breast or marrow for betraying us and not putting up a better fight. We fear what might happen if the problem gets worse, that the leg might never recover or that the cancer will take more than our breasts. And we are ashamed of the disabled or disfigured part: my breast has been mutilated; my colon is leaving a foul-smelling trail everywhere I go; my skin is full of scaly, plaques that make me look like a leper.

The feeling of alienation can easily intensify. After being angry or fearful or humiliated about the diseased part of the body, we begin to think of it as not our own. It can literally become a separate *it*. For how can this colon or marrow be part of *my* body, considering how selfish it is now acting? This is precisely what occurred to Oliver Sacks after he fell on a Norwegian mountain, injuring his leg. For a short but alarming period, the leg attached to his body (that he could neither feel nor move) was no longer his own, could in fact have easily belonged to someone else: he had lost it, he decided, staring down at the "thing" that used to be his leg (1998, 53).

Or the alienation becomes so profound that the body is not simply an object separate from us but an evil entity actively against us, an enemy that we must fight at all costs. A young woman suffering from chronic pain, a patient that Dr. Michael Stein discusses in his book *The Lonely Patient*, felt this way about her feet (2007, 17–57). Joanna's foot pain was a mystery which could neither be explained nor alleviated; it neither fit into a well-defined clinical condition nor responded to any conventional pain medication. After several miserable years passively watching her life unravel, all she could think about was destroying the enemy. *Get rid of them*, she pleads with Stein, the umpteenth doctor she has consulted with. *For God's sake, cut off those damn feet, I can't take it any more.*

The horror of Joanna's condition, a horror for all patients whose disease is not operable or curable, is the realization that the body *can't* be discarded, that it will remain with them and against them until they cease to be, that there is no escape.

Illness begins in the body and divides it, becoming at times a full-fledged, internal war.

### Estranged self

While we speak of illness and its effect on the body independently of its effect on the person, we do so unrealistically, mimicking the reductive manner of contemporary medicine. Feeling alienated from part of the body quickly expands into (or more accurately, can't be separated from) feeling alienated from our self. Sam is not just mad at his marrow but at himself, that somehow *he* is failing. Likewise Laura Denning's shame extends beyond her chest; her breasts aren't just appendages or accessories but very much an integral part of how she sees herself. And Joanna in a real sense doesn't merely want her toes gone but the rest of her, as she is in her current state, as well.

Language, the great twentieth century philosopher Ludwig Wittgenstein remarked, often deceives us about the way things are in the world (1958, section 115). We talk and have talked for centuries—a “we” that includes ordinary folk as well as a long list of philosophers and religious figures—of the body distinct from the mind. But are the two really separate and separable entities? Surely not in the way we experience them. As contemporary thinkers have persuasively shown, we are fundamentally *embodied* creatures, an embodiment that in turn is critical to the way we think about and construct our selves.<sup>2</sup> I am my thoughts and feelings just as much as I am my external appearance and body movements, all of which are inextricably related.

Nowhere is this more evident than in illness. When the body breaks down, so, too, does the self. Patients like Sam, Joanna, and Laura are angry at themselves, afraid for and ashamed of themselves. I feel disoriented, they might say, not just because my marrow or toes aren't cooperating, but because I, the global I, am not who I was anymore.

Oliver Sacks captures this progressively widening trajectory in his memoir, *A Leg to Stand On*. Like all patients, even those who happen to be physicians, Sacks initially focuses on his leg, badly damaged after his fall on the mountain. The muscles have atrophied and feel like mush. He can't lift the leg or wiggle his toes. More disturbing still, he can't see the extremity in his mind's eye. When the nurse tells him that his leg is on the bed, not hanging down from it, Sacks is beside himself; he could've sworn it was the other way around. Clearly, this is not the leg he once knew. Yet in the midst of the crisis, Sacks's surgeon informs him with the utmost confidence that the leg has been fixed and all would soon be well—“Continuity has been restored” was the phrase Sacks remembers hearing.

Yet all was surely not well, and continuity had not been restored—neither continuity within the leg nor continuity between the leg and the rest of Sacks. For just as he had physically contracted, now one leg short as it were, Sacks had contracted in a broader sense. He felt small, weak, vulnerable. In a matter of a few weeks, the once distinguished doctor had been reduced to a cloying child who could barely form a sentence in front of, let alone contradict, his doctor and his blatantly false proclamations. He felt “morally helpless, paralyzed, contracted, confined—and not just contracted but contorted as well into roles and postures of abjection” (1998, 131).

This shrinkage is a commonly experienced part of being ill; if it can happen to a man of Sacks's intellect, then surely it can happen to any of us. I remember feeling this way throughout my own encounter with illness, which began shortly after my medical residency.

<sup>2</sup> An excellent account of embodied consciousness can be found in Johnson, *The Body in The Mind* (Chicago, University of Chicago, 1987).

But there was one moment in particular: a Sunday afternoon in the hospital where I'd been in isolation for nearly 5 weeks, slowly recovering from a bone marrow transplant and desperately wanting to go home. One of the covering doctors whom I'd never met before entered my room. I was sitting in my chair, slumped and disheveled. He stood across from me, looming over the doorway, and bellowed like a drill sergeant: *You need to hunker down for the next few weeks*, he commanded, *until you're strong enough to leave*. Months later, I passed the doctor in the hallway and was surprised to find that he wasn't as tall as I remembered, nor was his voice particularly loud or deep. But that day he was a giant, imposing as the angry God of the Old Testament, and I was an insect—weak, vulnerable, terrified (Biro 2001, 223–4).

Illness diminishes us. It diminishes us physically and, as Sacks suggested, morally. We often regress to a child-like state. Worse, we may act out our aggression and insecurity on others. Ironically, in the midst of writing this essay, I threw out my back, a problem that resurfaces every few years. For 2 weeks, I walked around crooked, my right hip slightly higher than the left, and in constant pain. But I also became crooked in spirit. I was angry, intolerant, selfish—at home and also, I'm embarrassed to admit, in the office with patients. My God, I thought, was this really me? Could a muscle spasm in my back transform me into a monster overnight? Thankfully, the chiropractor was able to straighten me out in a few sessions, enabling me then to straighten out my horrendous behavior. It made me think of patients who aren't so lucky, who suffer without reprieve or the hope of reprieve. How do the chronically ill manage to escape their physical and moral diminishment? How does Sandy, a friend and patient who suffers from the daily joint pains and aches of rheumatoid arthritis, manage to be so giving, genuinely and joyfully giving, to her family and friends?

Illness alters us, makes us unrecognizable to ourselves. This is why Arthur Frank, a sociologist and cancer patient, talks of illness as a loss of destination and map (1995, 1). We lose our footing, become disoriented, and have trouble finding our way back (and our selves) again. I used to be a doctor, Sacks might have said, but now I'm a child. I was the manager of a successful restaurant, says Sam, but soon I may be out of a job. I used to love myself, says Laura, now I practically hate myself. If we wish to help patients, we can't ignore this breakdown of self. Continuity has been restored, Sacks is told by his doctor. To our physical being maybe but not necessarily to our person.

A continuity, moreover, which involves the present as well as the future. In illness, we become unsure of who we are and also where we are going. Sacks, who defines himself as an outdoors person, hopes to be able to climb mountains and bike again. Sam dreams of owning his own restaurant, Laura dreams of making films, and both pray they will be able to watch their children grow up. Such hopes, desires, and dreams are an integral part of our identities.

Illness threatens us. It threatens the way we see ourselves and ultimately our very existence. As Dr. Eric Cassell once wrote: "Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some manner (1991, 33)".

When we are sick, we stand face to face with our mortality. Will I survive breast cancer? Laura wonders. Will I be around to see Ruby graduate from high school, to be at her wedding, to help care for her children as my mother is caring for me now?

Illness, recalls Mark Doty while caring for his lover with AIDS, is rife with anticipation: "It surrounds us with the vertiginous, the branching paths of what *could* happen... it suspends us in not knowing" (1997, 203–4). Such uncertainty is clearly magnified when a disease is poorly understood. Doty's lover contracted HIV in the 1980s when the experts had no idea how to treat patients, let alone prognosticate. The future was terrifyingly



opaque. How does one live like this? How does one prop oneself up and summon the courage to go on? Doty's memoir, *Heaven's Coast*, offers us a heart-wrenching inkling into the daily stream of fear, anger, shame, jealousy, and loneliness unleashed by the ongoing threat of illness.

Entering the land of the ill, personally or vicariously (caring for loved ones or listening to and reading the stories of patients), we quickly realize how consuming the experience is. How can we possibly think of it solely in terms of a body that has broken down and must be fixed? Illness shakes us to the core of our being. The entire edifice comes apart at the seams; the centre, in the words of W.B. Yeats, cannot hold (1973, 131). Patients grope for support to hold themselves upright. Every time Sam thought about what was happening to him, he reached for the side of a chair or positioned himself against the wall to keep from falling—not just his body but him, his life, his family, his dreams.

We mustn't underestimate the systemic effects of illness, its sheer density and reach. Patients feel lost, out of control, estranged from themselves and most horrifying at times, on the verge of extinction. This is why it shakes them so: why they feel like falling; why they can't think of anything else and obsess about their symptoms; why they demand reasons and explanations; and why they get exasperated when doctors, the experts in their white coats, look at them blankly and say that they can't answer their questions. It's not possible, they insist. There must be a reason, something in the air, the food, something I did or thought about doing, something my parents did.

If we don't appreciate the gravity of illness, we won't ever be able to truly comfort patients, let alone begin to heal them.

## Estranged world

The ill suffer because they feel threatened. But they suffer just as much, if not more, because they feel isolated from others, because they feel alone. So the circle widens once again: the body unravels, the self unravels, and now our relationship with the world unravels.

As it must, for while we value our personal selves, we don't live on separate islands like Robinson Crusoes but in communities, constantly engaging others in our actions and thoughts. This social embeddedness is just as important to who we are and how we define ourselves as our bodies and minds, our embodied selves (Merleau-Ponty 1962, xi). So it shouldn't be surprising that we become disoriented and distressed when this shared grounding begins to disintegrate. In fact, the loneliness of illness—what William Styron, the novelist who suffered from depression, called its “aching solitude” (1992, 46)—can be as painful and literally killing as the most aggressive cancers and the worst physical pain (Cacioppo and Patrick 2009, 92–109).

One of the most striking images of illness's solitude comes from Jean Dominique-Bauby. At 42 years old, the French journalist was on top of the world. The editor of *Elle* magazine, Bauby was married, had two children, a steady stream of mistresses and plenty of money to fund his extravagant lifestyle when suddenly the curtain drops. After suffering a major stroke, Bauby wakes up in a hospital room to find that he is almost completely paralyzed; the only part of his body he can still move is his left eyelid. Neurologists call this thankfully rare condition locked-in syndrome. While he is surrounded by people, medical personnel and family, Bauby has no way of reaching them. He can't talk, put his hand out to gesture, or barely even see. He is completely shut out from the old world and alone in this strange and horrifying new one where he will remain for the rest of his short life. In his mind and then in the book he miraculously manages to write by blinking his good

eyelid, *The Diving Bell and the Butterfly*, he imagines himself imprisoned in an old-fashioned diving bell, sinking and further into the ocean depths, away from all that he once loved (1998, 4-5).

Of course in Bauby's case, the exile is extreme and quite literal. Because of his physical disability, he can only make contact with other people by the most extraordinary means. But every patient feels exiled to some degree—from the teenager with acne who won't leave the house to patients with chronic, debilitating diseases to those with life-threatening cancers. Loneliness is by far the most commonly reported and distressing complaint of the ill. "I am in bed with influenza," Virginia Woolf wrote more than a century ago, "while the whole landscape of life lies remote and fair, like the shore seen from a ship at sea" (1967, 195). When Oliver Sacks fell on the mountain in Norway and there was no one around to help him, he feared the worst, that he would never be rescued. But his sense of isolation did actually get worse, *after* he was safe and secure in the hospital. Safe but with a leg he no longer knew: "I became all of a sudden desolate and deserted, and felt—for the first time, perhaps, since I had entered the hospital—the essential aloneness of the patient, a sort of solitude which I hadn't felt on the mountain" (1998, 65).

Sam talks about an impenetrable wall that leukemia has erected around him. In the past, he had always been outgoing, someone who liked to slap friends on the back and embrace his mother and father in bear-hugs. But the wall now empties these gestures of meaning. People avoid him as if he were not the same person anymore. Whether real or imagined, the barrier between him and others has become unbridgeable. Most distressing of all, the wall has invaded his home. Even with his wife and son, he feels shut out. He sees the hesitation in their eyes—is it because he looks different, because he can't be relied on, because he may not be around much longer? He hears their unspoken questions and wants to assure them but doesn't know how.

Even the most well-adapted to illness acknowledge the presence of the wall. Now in her forties, Sandy has lived with rheumatoid arthritis for over 20 years. It began in college and instead of the typical gradual course, the disease galloped along at breakneck speed attacking almost all the joints in her body, large and small. She has since suffered years of unrelenting pain, joint replacements to both hips and both knees, and aggressive medications with often severe side effects. Nevertheless, Sandy adamantly claims she doesn't feel isolated, at least not so much anymore. Because of her remarkable will and strong support system of family and friends, she has been able to re-integrate herself into the world of the healthy, an almost seamless assimilation. Yet even Sandy has her moments. At night, for instance, when she wakes up in pain and looks down at her husband sleeping beside her, peacefully and ignorantly, she realizes, no matter how much she might try, she can never completely banish the feeling that she's in this thing by herself.

There are numerous reasons for the aching solitude all sick people experience to some degree. In the first place, illness defines patients as different. They may be visibly different like John Updike and his scabby, psoriatic skin (1989, 42). But even when the problem lies deeper within the body, patients with heart disease or early cancer, for example, who look and feel fine, the ill are marked. Viewed as a departure from the norm of health, as ab-normal, illness is a source of embarrassment that can lead to self-recrimination; patients often blame themselves for becoming sick; they feel guilty, as if they had committed a crime and should be punished (Karinthy 1992, 64 and Murphy 1990, 92-4).

The ill are also marked by the acknowledgement of their mortality. Illness anticipates, at times very palpably and at others more subtly, the end of life. Patients feel this sense of doom hanging over their heads, which makes them jealous of the healthy who typically do not. What makes matters worse is patients feel that others are also aware of their uncertain futures. That's partly why the healthy seem to shy away from them, why Sam's wife and



people at the restaurant shy away from Sam, as if they too are preparing for the possible loss of their spouses, siblings, friends, and colleagues.

A second reason for feeling apart is that illness instinctively turns us inward. Ordinarily, we are fundamentally outward-facing creatures, looking into and engaging with the world in most everything we do. But illness radically changes that. Our bodies, which typically remain silent in health, now speak to us. They tell us, loudly and in no uncertain terms, that something is wrong, that our bodies can no longer perform as before and may not be able to keep going. These SOS signals in the form of pain, fever and other symptoms not only can't be ignored but also must be closely attended to. And so, like the mollusk, retreating into its shell, our priorities shift. Where once we focused on the outside world—our jobs, our friends and family, pleasurable activities—now we obsess over the inside one. What becomes most important, indeed critical, is the marrow that is failing, the joints that cause excruciating pain with every movement, the mind descending into the darkness of depression.

Illness sets us apart, then, by making us look and feel different from others and by shifting our focus from the external to the internal world. But what solidifies this separation is the unsharability of the experience. Our feelings are private. They can never be adequately known by or communicated to a doctor, a friend, or even a wife or husband. Here is the wall that Sam and so many other patients imagine has sprung up around them. Other people, no matter how close, can never feel what we feel—neither the physical aspects of illness (the pain, aches, and other strange sensations) nor the emotional ones (the fear and rage, shame and vulnerability).

Of course one might argue that the wall is simply a fact of human existence, that we are always separated from one another, by our inner experiences, by the outer layer of our bodies, by the particles of air floating between us. But illness and especially pain seem to exaggerate these boundaries. They are situations when the wall is at its most impenetrable (Biro 2010, 23–35 and Toombs 1992, 22–5). If others can't know how we feel and if we can't adequately convey this information through language or some other means, then we really no longer occupy the same world: the ill person is on one side, everyone else on the other. This may be the most terrifying epiphany of illness, what Sandy felt in the middle of the night, looking down at her husband: he will never know.

Finally, we must recognize that the solitude of illness is not merely in the mind of the sick person. For those on the far side of the wall also bear responsibility. In fact, as much as the ill turn away from the world, the world turns away from them. It does so partly because the healthy would like to maintain the fantasy that illness is not a natural part of life, that somehow they are immune to decay and dying; partly too for more selfish reasons since the ill can often be a burden with their lengthy lists of complaints and needs; and partly because the stigma of illness is also embarrassing for the healthy, causing even well-intentioned outsiders to feel and act awkwardly in the presence of the ill (Murphy 1990, 108–136).

Perhaps most of all, the healthy turn away because they, too, recognize the tenacity of the wall, that it is just as unbreachable for those on the outside as it is for those on the inside. "For who when healthy can become a foot?" wrote W.H. Auden in his poem "Surgical Ward":

Even a scratch we can't recall when cured,  
But are boisterous in a moment and believe  
In the common world of the uninjured, and cannot  
Imagine isolation. Only happiness is shared,  
And anger, and the idea of love (1989, 73).

Patients like me and so many others are always shocked by the deafening silence of those around us. Yet the problem is not a lack of sympathy, as Auden intuited, but a lack of imagination. Healthy people simply can't fathom a form of anguish so foreign to everyday experience. If we've never descended to the depths of lupus or leukemia or depression, how can we possibly know what it's like? Even the most imaginative among us, our greatest writers, may come up short. William Styron, for example, recalls how chillingly indifferent he had been (when healthy) to his good friends who were depressed at the time (1992, 25–6).

For reasons both internal and external to the experience, then, the ill person inevitably feels alone. This is why illness gives rise to so many metaphors of isolation: illness as wall; illness as journey (Sontag's "night-side of life" (1977, 3) or Mann's faraway Magic Mountain); illness as exile (Sophocle's Philoctetes on a deserted island); illness as prison (Bauby's diving bell). Patients feel this way when they are literally alone but also when they are surrounded by family and friends, as Sacks felt in the hospital and Sandy in her bedroom.

The ill inhabit a different world, one that is not only spatially but also temporally apart (Toombs 1992, 68–70). Their world is both far off and runs on a different clock. Time becomes severely distorted, typically slowing down, anguishingly so as patients wait for test results, a dreaded checkup, or an MRI scan that will reveal who knows what. Or time keeps repeating itself, replaying our pain and discomforts, conversations with doctors, fears about the future over and over again. For the healthy, by contrast, time sails on without a hitch; it flies.

## Overlapping circles

Illness is always a more fluid than static experience. At times, we focus primarily on the body and its betrayal. At others, we think more about ourselves, the change from what we once were and the uncertainty about the future. And at still other times, we fixate on relationships with other people, the strain on those relationships, our feelings of exile. But the truth is that each of these frames are intimately connected, constantly moving the sick person back and forth between narrower concerns and more encompassing ones.

Lucy Grealy's story is a perfect example of this interconnectedness. It begins, she tells us in her memoir, *Autobiography of a Face*, at age nine with a rare form of cancer that grew in her jawbone. After the removal of the tumor and several rounds of chemotherapy, Grealy is left with a deformed face: strangely triangular, as she describes, and accentuated by the fact that she is unable to keep her mouth completely closed (2003, 3). There would follow a seemingly never-ending series of operations to correct the defect. Each procedure offers renewed hope which is eventually dashed as the bone grafts repeatedly fail.

On the surface, Grealy's problem involves the body, a relatively small part of the body albeit a highly visible one. And she works hard to conceal the "broken" and embarrassing part. She grows her hair long. She wears bulky turtlenecks. She twists her head when people talk to her so that only the good side shows. But like the series of plastic surgical procedures, these strategies are never very successful.

Never successful, because the problem is more than a broken face. Grealy, the person, is also broken. When she looks in the mirror, Grealy is either disgusted (I am ugly) or feels disconnected (who is that?). She sees someone who is not herself or *any* self for that matter since the parts don't add up to a whole. That is not me, she says, but an imposter. And what is precisely "me" will elude Grealy for the rest of her life. Clearly, the timing for such self doubt couldn't be worse since cancer interrupts Grealy's life just when she is in the processes of forging an identity, those critical teenage years. So it shouldn't be surprising

that the deformity quickly spreads from the jaw to her person. I *am* my face, she decides, I *am* ugliness (2003, 7). Which is why the turtlenecks only conceal part of the problem. The rest of herself must also be hidden. She becomes a perpetual back-peddler, retreating from the center of things to the sidelines and shadows.

Grealy feels safe in the shadows because there she is invisible to herself and to others. Even when she's alone in her room looking at herself in the mirror, the world is with her, looking over her shoulder and miming her disgust. The circle continues to widen. We construct our identities with the thoughts and actions of *other people* as much as we do with our own thoughts and actions. Young Grealy learns this soon after her first surgery when she takes a job at local horse stable that provides pony parties for children. The parties would start off well, the children's enthusiasm when they first see the ponies is contagious. But as the initial thrill subsides, all eyes turn on Grealy and her disfigured face. *What's wrong with her?* the children ask with their stares. She would reply with one hiding tactic after another but could never completely evade her interrogators: "Their approval or disapproval defined everything for me, and I believed with every cell in my body that approval wasn't written into my particular script. I was 14 years old" (2003, 4). Those stares, real and imagined, will be a source of profound shame and guilt throughout her life.

Forever on the run, from herself and from others, Grealy will never be happy. She lives in a diving bell like Jean-Dominique Bauby, far away from the world: When I tried to imagine being beautiful, I could only imagine living without the perpetual fear of being alone, without the great burden of isolation, which is what feeling ugly felt like (2003, 177).

And this loneliness, she explains, is infinitely more painful than any physical pain she ever experienced from cancer or chemotherapy or the countless surgeries. So much so that after years of trying unsuccessfully to assuage it, she cannot go on any longer. Suicide is the only escape she can see for herself.

Illness is a complex, multi-layered experience. Circles fanning outward from the body to the person to the world, then back inward, each one characterized by alienation and fragmentation, by being different and no longer whole. These characteristics in turn generate a host of other commonly experienced emotions: anger, fear, vulnerability, helplessness, shame, and loneliness.

To be sure, certain illnesses tend to emphasize some emotions over others. In Grealy's case, the cancer involves the most visible part of her body, her face, so that shame becomes the most distressing part of her experience. The same may be true for patients like John Updike, whose skin is covered with psoriatic plaques, and Robert Murphy, confined to a wheelchair which literally shrinks him to half his former height (and self); and for patients with less visible deformities like Laura Denning, ashamed of her disfigured chest and John Donnelly, ashamed because a part of his body, normally hidden from view and smell, begins to surface. But even in illnesses where the problems are imperceptible, shame can be consuming. A diagnosis of AIDS or cancer, or the attitudes of society towards such diseases, as Susan Sontag showed us in her groundbreaking studies on illness and metaphor, marks patients as alien, for whatever reason we manage to concoct at a given time in history: the wrong sexual orientation, sinful behavior, or repressive personalities.

In other illnesses, fear and anger may predominate, especially when there is a high level of uncertainty. Cardiac disease destroys silently and invisibly, carrying a more favorable cultural label than cancer, but what it lacks in shame is more than made up for by a constant state of fear. While spared the prolonged, ugly death we associate with cancer, the cardiac patient can die suddenly at any time and in any place. The anxiety this often produces also haunts patients with diseases whose trajectories are difficult to predict. The young poet

Sarah Manguso developed a rare neurological condition during college that paralyzed her for weeks at a time. But even when seemingly free from its clutches, 7 years into remission, she tells us in her recent memoir, *The Two Kinds of Decay*, her life has been and continues to be far from normal. After much rationalizing, Manguso finally acknowledges why she's never owned a car, held a permanent job, or entered into a long-term relationship:

The real explanation is that I haven't lost the fear that at any moment I will have to quit my job, say goodbye to my friends, leave my home, and go to the hospital not knowing when, or in what condition, I'll be discharged... My disease has been in complete remission for 7 years but I still act as if I expect it to come back tomorrow (2008, 159).

The same uncertainty consumes patients with "new" diseases like AIDS in the early days of the epidemic. As the memoirs of Paul Monette and Mark Doty show, living with AIDS at this time was like living in a Kafka novel. Even at the best institutions, physicians didn't know what was happening to patients or how they might best be treated. "These years," writes Monette in *Borrowed Time*:

Have taught me that fear—terror, that is, with a taste like you're sucking on a penny—is equal parts rage and despair. The panic makes your brain race so fast that yelling spews like poison food and the blackness flattens you, without any back-and-forth like day and night, not even any contrast. You are up and down at the same time (1988, 48).

But despite these differences in quality and degree, the emotional landscape of illness remains relatively constant. All patients experience shame to a certain extent. It was present for Sam whose appearance hadn't changed much, in his concerns that he might not be able to provide for his family or succeed in his career. Likewise, Grealy felt the fear that is equal parts rage and despair. Her cancer could come back; the next surgery might not work; she might never be loved.

And certainly, all patients feel isolated. Even those like Sandy who appear to have fully assimilated, even they feel alone at times. The ill are different, set apart from others, their experiences private. For some like Lucy Grealy, the isolation can become so painful that they lose hope of ever returning to the shared world. Too far out in their diving bells, they choose to end the pain by ending their lives.

## Conclusion

The ill have been silent for much of history, a silence that has for the most part been imposed on them by the outside, healthy world and that has prevented doctors and caregivers and policy makers from fully understanding and responding to their needs. Today the outside world is in a position to reverse this unhealthy trend. In the last few decades, the ill have rebelled against their assigned role of docile patient and have begun to reclaim their voices (Frank 1995, 7 and Hawkins 1999, 3). They are speaking out in the clinic and on the Internet, creating patient advocacy websites like Christine Miserandino's. They are making pictures and movies about their experiences, like Deborah Padfield's photographs of chronic pain (2003) and Lori Benson's documentary about living with breast cancer (2006). They are writing essays and books, famous patients like William Styron as well as ordinary ones like me. Let's seize this opportunity and listen, for the ill have a great deal to teach us about illness and healing.

Citizens of the day-side of life—medicine and society as a whole—will learn from these bold, new night-siders that illness entails more than fever, pain, and other somatic symptoms. Equally important are the existential complaints that follow in their wake: the anger and fear, the vulnerability and shame, the “aching solitude.” Except in extremely brief and successful encounters with illness, we can’t expect to heal patients with surgery and chemotherapy alone. We must also repair their broken selves and broken connections to the world. Most patients need strategies to cope with the uncertainties of illness, to find hope in desperate situations, to bolster their vulnerable egos, to remake their self-narratives, and to alleviate their loneliness.

We will learn too that not only aren’t we always helping the ill, but in many instances we are actually making matters worse by segregating them, labeling and stigmatizing them, treating them as unfeeling objects, even humiliating them at times. All these actions on the part of the healthy world exacerbate the existential symptoms of the ill, and in doing so, as Arthur Kleinman and Eric Cassell have warned, exacerbate their suffering (Kleinman 1988, 9 and Cassell 1991, viii, ix).

In this new era of healthcare consciousness and reform, we can no longer afford to ignore the ill. If we truly wish to improve their lives, then we had better listen to what they have to say.

## References

- Auden, WH. 1989. “Surgical Ward.” In *Selected Poems*, ed. E Mendelson, p. 73. New York: Vintage International.
- Bauby, Jean-Dominique. 1998. *The Diving Bell and the Butterfly*. New York: Vintage.
- Biro, David. 2001. *One Hundred Days: My Unexpected Journey from Doctor to Patient*. New York: Vintage.
- Biro, David. 2010. *The Language of Pain: Finding Words, Compassion, and Relief*. New York: W.W. Norton.
- Cacioppo, John T. and William Patrick. 2009. *Loneliness: Human Nature and the Need for Social Connection*. New York: W.W. Norton.
- Cassell, Eric. 1997. *The Nature of Suffering*. New York: Oxford University Press.
- Doty, Mark. 1997. *Heaven’s Coast*. New York: HarperPerennial.
- Donne, John. 1999. *Devotions Upon Emergent Occasions and Death’s Duel*. New York: Vintage.
- Frank, Arthur. 1995. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Freud, Sigmund. 1959. “Inhibitions, Symptoms, and Anxiety.” In *The Standard Edition of the Complete Philosophical Works of Sigmund Freud*, ed. and trans. J Strachey, A Freud, A Strachey, and A Tyson, p. 171. London: Hogarth.
- Grealy, Lucy. *Autobiography of a Face*. New York: HarperPerennial.
- Hawkins, Anne Hunsaler. 1999. *Reconstructing Illness: Studies in Pathography*. West Lafayette, Indiana: Purdue University Press.
- Johnson, Mark. 1987. *The Body in the Mind*. Chicago: University of Chicago Press.
- Karinthy, Frigyes. 1992. *A Journey Around My Skull*, trans. V. Barker. Budapest: Corvina.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Manguso, Sarah. 1952. *The Two Kinds of Decay*. New York: Farrar, Straus and Giroux.
- Mann, Thomas. 1952. *The Magic Mountain.*, trans. H.T. Lowe-Porter. New York: Random House.
- Merleau-Ponty, Maurice. 1962. *The Phenomenology of Perception*, trans. C Smith. London: Routledge & Kegan Paul.
- Miserandino, Christine. “The Spoon Theory.” [www.butyoudontlooksook.com](http://www.butyoudontlooksook.com).
- Monette, Paul. 1988. *Borrowed Time: An AIDS Memoir*. Orlando: Harcourt.
- Murphy, Robert F. 1990. *The Body Silent*. New York: W.W. Norton.
- Padfield, Deborah. 2003. *Perceptions of Pain*. Stockport, UK: Dewi Lewis.
- Sacks, Oliver. 1998. *A Leg to Stand On*. New York: Touchstone.
- Sontag, Susan. 1977. *Illness as a Metaphor*. New York: Vintage.
- Stein, Michael. 2007. *The Lonely Patient*. New York: HarperCollins.

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- Styron, William. 1992. *Darkness Visible: A Memoir of Madness*. New York: Vintage.
- Toombs, S. Kay. 1992. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Dordrecht: Kluwer Academic Publishers.
- Updike, John. 1989. *Self Consciousness: Memoirs*. New York: Ballantine.
- Wittgenstein, Ludwig. 1958. *Philosophical Investigations*, ed. GEM Anscombe, R Rhees, and G.H. von Wright, trans. GEM Anscombe. Oxford: Blackwell.
- Woolf, Virginia. 1967. "On Being Ill," in *Collected Essays*. New York: Harcourt.
- Yeats, William Butler. 1973. "The Second Coming," in *The Norton Anthology of Modern Poetry*, ed. R Ellman and R O'Clair (New York: W.W. Norton) p. 131.