# HOW TO WRITE ILLNESS

Marianne Manzler

A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Fine Arts

University of Washington
2019

Committee:
David Shields
Rae Paris

Program Authorized to Offer Degree:
English

University of Washington

Abstract

# HOW TO WRITE ILLNESS

Marianne Manzler

Chair of the Supervisory Committee:

David Shields

Department of Creative Writing

When it comes to writing illness, our bodies are contested, questioned, consumed. Our bodies are controlled and maintained. When there is a physical or psychological rupture in a person's relationship to their body, self, and surrounding world, is there a temporal disruption that occurs and calls into question their identity, capabilities, life projects? How do they cope with the disruption of self, or begin to reconstruct their story? And can these stories even still be called narratives, in their often radically fragmented form? This critical essay seeks to define the types of illness narratives that exist and study how these stories help people make sense of the world, how these texts work as both art and strategy for navigating lived experience, such as time, process and change. Through the following nonfiction narratives of Alphonse Daudet's *In the Land of Pain*, Audre Lorde's *Cancer Journals*, and Susan Sontag's *Illness as Metaphor*, I seek to understand how psychological and physical trauma and their sociocultural contexts shape the composition of these autobiographical accounts and the ways in which their ill subjects reconstruct (or evade reconstructing) their lives around their disease.

# INTRODUCTION

When disease becomes synonymous with stasis, no longer compatible with plot of any kind, what are the implications of an illness narrative that is un-narratable in the traditional sense? After all, what is a story without the conventional narrative arc, and in the absence of those traits, how do writers maintain literary momentum throughout their story?

"One would have thought," writes Virginia Woolf in *On Being Ill*, that "novels… would have been devoted to influenza; epic poems to typhoid; odes to pneumonia, lyrics to toothaches" (4). Even in the aftermath of the 1918 influenza epidemic that affected over one-third of the globe's population[1], illness remained unseen and marginalized by silence. The story of the body, it appears, "lacks plot" (6). Woolf, who suffered from migraines, also laments how little literature has to say about illness and the sick body:

> "Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to light . . . it becomes strange indeed that illness has not taken its place with love, battle, and jealousy among the prime themes of literature." (3)

This passage packages wisdom so neatly and tightly that it calls attention to its own construction, seeking to instruct its reader on illness as both a "common," ordinary

---

[1] https://www.cdc.gov/features/1918-flu-pandemic/index.html

experience shared by many (too commonplace to even merit representation) but also as one that can bring about intense "spiritual change." Here, Woolf's writing is marked by its suspended syntax to heighten the inevitability of her argument. We almost lose sense of time altogether. We simply have to follow the intent of a mind that attempts to reason its way through illness by the sentence's end. Woolf treats illness as if it is a dramatic performance, and once the "lights of health go down," she begins a new scene in which one's sickness becomes a place of artistic expression. She uses careful patterns of repetition (a series of subordinate clauses—*how, how, when, what*) to explore the relationship between language and illness, believing that the absence of illness and embodied suffering from literature stems from the writer's inability to articulate the pain of suffering and the reader's failure to ever fully comprehend another's illness.

As a cancer patient, my approach to illness and recovery was contested and muddled by my own background in my body's uncontrollable movement from healthy to sick to "healthy" again, as I found that the duality of self extended far beyond health and disease, and for me, existed long before my illness revealed itself during my Fulbright teaching assistantship abroad. Cancer forever changed the landscape of my body, a series of shocks that warped my sense of time and self, and I found that when in crisis, my natural inclination was to rely upon storytelling to shift the attention away from my ailing body, and instead towards words, sentences, a narrative that could capture what it meant to face my own mortality. The narrative is a symptom of control, and this desire to narrate life becomes even more pressing when paired with the antithesis of control, disease. Anatole Broyard wrote in *Intoxicated by my Illness*, his autobiographical account about life with cancer, "the sick man sees everything as metaphor" (7). And he was right—despite medicine's hopes to fix my body, I felt the slow bleed of uncertainty and banal fatigue, of having an illness without any particular causality, until I could feel nothing else. Like writers-turned-patients such as Alphonse Daudet, Susan Sontag, and Audre Lorde, I also sought to find the essential truth of my experience, to reckon with illness through literature, and to above all, do anything but suffer silent and alone.

Less than a year into remission, I began writing a book-length project that explores the clash of two powerful communities—culture and science—and how the manifestation of an illness causes me to reckon with my identities as a daughter, a Filipino-American, an artist, an expatriate, a friend, and a lover. Two years later of piecing together this narrative has led me to question what it means to write about illness and how the deliberate act of remembering and retelling is crucial to not only the drafting process, but to the works' composition as a whole: How does one begin to reconstruct (or avoid reconstructing) the lived experience of displacement within a narrative? Where does my story fit into this tradition of illness and suffering, one that started long before me and will continue long after?

If the literary expression of selfhood is the crux of illness narratives, then so is the potential for personal autonomy when it comes to how and why a writer reclaims the events of their life. The concept of reclamation drives three narratives, Alphonse Daudet's *In the Land of Pain*, Audre Lorde's *Cancer Journals*, and Susan Sontag's *Illness as Metaphor*, to approach the risk, the prognosis, and the pain of illness in three very different and informative ways. *In the Land of Pain* is a collection of Daudet's notes and urgent missives spun from the painful realities of chronic illness. He sets out to write a book about illness, and in this work's resistance to a traditionally plotted story, perhaps it succeeds as one that more closely embodies suffering. Sontag's *Illness as Metaphor* can be considered anything but a memoir; in fact, Sontag rarely appears in the text. Her book, which argues for the elimination of all metaphorical thinking from our responses to illness, almost certainly would never have been written, says her son in the preface to a collection of Sontag's private journals, "had it not been for her experience of the stigmatization that came with cancer." Lorde's *Cancer Journals* blurs memoir and journal in order to grapple with the political, social, and personal costs of a radical mastectomy as she copes with the silence and invisibility of cancer. She challenges the inequities of cancer, a disease borne at the intersections of oppression faced by Black women and the resistant power of language. There is a political call to arms and community force present in her illness struggle that is absent from the other two. Through these memoirs, I seek to understand how we write about illness, or as Broyard says, find the "style" of disease. I need to know: is it possible to tell these experiences in a meaningful, compelling way that speaks to the gravity of what is happening to that individual? That captures the interconnected identities of class, gender, ethnicity, ability, age, religion, and the historical and cultural context in which that writer exists? And if so, what are the ways to successfully do this? This essay will explore how three writers—Daudet, Lorde, and Sontag—navigate the psychological and physical disruption of their illness and interrogate what it means to write their way back into visibility, as patients, as artists, as people.

# RECONSTRUCTING ILLNESS

Any illness constitutes an obstruction to an ongoing life, altering or calling into question everything we know about our identity, capabilities, and life projects. A sense of stagnation sets in with the uncertainty of health and thus, the future. This disruption of self, whether it is acute or chronic, causes both a physical and psychological rupture in a person's relationship to her body, self, and surrounding world, shredding one's very understanding of what it means to exist outside of one's symptoms or disease. *In the Land of Pain*, originally titled "La Doulou" (*The Pain*), was all but forgotten until 2002, when translated and supplemented with extensive annotations and re-published by Julian Barnes. Daudet, who contracted syphilis in his twenties and dealt with the excruciating onset of neurosyphilis in its tertiary stage, describes the effects of the illness that eventually takes his life in the 1890s: "Pain is always new to the sufferer, but loses its originality for those around him. Everyone will get used to it except me" (62). The novelty of sickness wears away quickly, and the world does not stop. Daudet's collection of observations, which condenses a decade or so of trauma to fifty pages, reveals how an illness narrative can work successfully: through a formally inventive structure, through compression, through the fragmented mediations of sex and love and injury. To say, though, that there is no progression or narrative arc is false, particularly when the structure the book seems to develop organically as a reflection or result of the content: a series of aphorisms, bursts of prose and white space that echo or reconstruct the disorienting experience of illness.

"You have to die so many times before you die," Daudet writes, encapsulating much of what I felt during the lowest, most painful time period of my cancer treatment (45). My time was held together by pain, where each injection or scan marked the passage of time. Feeling too much became a lot like feeling nothing at all. When reading Daudet's short, yet compelling story of pain, I was fascinated by the structure of the narrative: because time and space are often left out of the narrative, we have no sense for anything other than the pain of one individual. We sense the guilt and burden of his illness and how this might affect his wife and children, but only experience this as a periphery of his body's increasing debilitation and pain: "Musing on suicide…One doesn't have the right" (45). This sentiment is the closest that Daudet comes to politicizing his illness, and perhaps his book falls short of Sontag and Lorde in that he never contextualizes his illness or plight as a very wealthy writer of high Parisian society. He relies on the company and assistance of his family (at one point, everyone in his family from his wife to his father-in-law give him pain numbing injections), but these people are never developed as fully fleshed characters or humans outside of where they are positioned in relation to his body. Community is what sustains him in his weakest, most uncertain moments. In my own story of pain, fully developing both the narrator's identity and the multifaceted, complicated layers of how she exists within and as a result of her community are essential to the overall project. In a way, I've learned from the absences in Daudet's narrative, seeing how important it is to articulate the shifting relationships of bodies to memory to people, as we are shaped by ethnic and gender identities. I exist in a genealogy of pain and illness, and to ignore the context of my surroundings, of where this pain exists in time and place, comes at a steep cost of ignoring the origins of my body and my culture's suffering.

Daudet, overly conscious of his writerly self, ends up questioning the very premise of his book. He's unable to choose a proper mode that he believes can adequately capture what it means to suffer. This preoccupied him until his death—he even considered making himself unmarried in his book to highlight his suffering alone—but none of his pain would be possible to know if not for the confessional form of his notes that give us an understanding of his consciousness. No other form could do him justice. The note-taking form, episodic rather than narrative, is best suited for this type of project, as it allows it him to "talk about everything, without the need for transition" (22). When it comes to chronic illness, no real transition exists. His days are marked by the "sterility" (85) of stagnation, where days blur together, delineated only by morphine injections or the repetitive toll of the condition. Daudet suffered from a form of neurosyphillis where his body was quite literally wasting away, and in his case, the disease manifested itself in two ways: locomotor ataxia (loss of coordinated movement) and paralysis. Daudet's progressive paralysis and pain led him to try all kinds of treatments, no matter how bizarre or violent: he was injected with a solution extracted from guinea pigs; at the recommendation of Charcot to try the Seyre suspension, the author was strung up in the air by the jaw for several minutes. He did this thirteen times, each barbaric attempt meant to stretch his spine and loosen his joints and relieve the ataxia, until they stopped because he began coughing up blood. His notes on the treatment, all sentiment scrubbed from the prose: "No observable benefit."

Entries are not dated, though it is generally understood to be chronological; many entries are often no more than a few sentences long. Even without knowing how much time passes between each entry, there is still a sense of progression held together by his emotional estrangement and attempts to regain agency in the face of a debilitating disease, through any means possible. The fact that his notes are written "in the intimacy of a notebook [where] I can guide my pen as I choose" (67) lends itself to the agency of the author and authenticity of the narrative, unrevised and unchanged from its original, pained form when the words were first conceived. Compressing emotion into such a small, restricted space actually allows him the freedom to better express how his body feels, puts the power of structure into his hands as he allows content to shape form. In a way, if there is less space to fill, perhaps this becomes a less taxing project for him to envision completing as his disease "infiltrates" him—in the same way that he does not want to get better, but merely "keep on at the same level" (58). Daudet rejects a traditionally plotted narrative in favor of one that makes room for the disabled body and allows him to experiment with the ways of living as a writer with syphilis. He uses humor: "This resort for anaemics has its funny side. No one remembers anyone's name; brains are racked all the time; there are great holes in the conversation. It took ten of us to come up with the word 'industrial'" (105) to lighten the heaviness of the reading. Or later when Daudet is caught in an uncontrollable episode of ataxia, he compares his seizing leg to a "knife-grinder" in order to make the drama of illness feel ordinary. In one entry, he lists the "varieties of pain," first from the "hideous pain from light reflected in a window"(37) to more physically taxing symptoms, "hyper-sensitivity of the skin, loss of sleep, then coughing up blood" (39) in a list that compounds upon itself, each one revealing how overwhelming and consuming his disease is. But so be it: “That’s the disease for you,” he writes. In quick, digestible entries, he makes illness readable. The form, a resistance against stagnation, scatters as his condition worsens, then when all seems almost lost, coalesces into a sustained, imagined dialogue at the end. His writing is thematically cohesive, rather than traditionally plotted, as a way of staying true to the fractured state of illness.

We learn that he will lose all physical control of his own body over time, and his book charts this loss of humanity through his disease’s attack on his ability to read or write—confirmation that he must face a disease that he knows will ultimately destroy his life. The cruel reality is that he has “passed the stage where illness brings any advantage or helps you understand things; also the stage where it sours your life, puts a harshness in your voice, makes every cogwheel shriek” (65), but reading and writing are still one of his few options of leisure or meditation. If he can manage to string together a few sentences, he will. Daudet tries to hide the deterioration of his condition from his family and friends as best as he can, but his disease becomes so detrimental he can’t even hold a pen—“I find it impossible to write an address on an envelope where I know that people will read and examine it” (67). Or when reading, suddenly “objects appear cut in two, the page of a book, the letters of a word only half read, sliced as if by a billhook… I grasp at letters by their downstrokes as they rush by” (41), and it becomes clear to the reader that these slender hundred pages emerged from immense pain and focus because his notes were his only refuge. “My existence is effectively over,” he says. “I love only through the novel—that’s to say, through the lives of others” (90). While living, he sees himself through his words—unable to fully articulate to his family the truth/extent of his pain—

but in death, sees true survival through his offspring. One of the greatest contradictions he claims is that he viewed his book as “the result of an act of expansiveness, an expenditure of energy, which could equally have manifested itself differently” (105), or in other words, his life’s work was nothing more than a diversion, when it is the act of recording that keeps him sane through his most barbaric treatments or frequent injections of morphine. Writing about illness requires the kind of “unheroic” and stoic quality that this statement exhibits, which is undercut by the flippant addition of “equally have manifested itself differently,” subtly pointing to Daudet’s desire to be useful, to live on in death, to be something other than sick. He says he does not care, but we know anything but that is the truth. To not care is less painful to claim. Daudet is pictured as a flailing patient, addicted to a number of palliative drugs (bromide, chloral, and morphine) with only his notebooks as his only weapon against pain, as he searches for language to match his suffering: “Tonight, pain in the form of an impish little bird hopping hither and thither,” he writes. “Pain finds its way everywhere, into my vision, my feelings, my sense of judgment; it’s an infiltration” (67). To Daudet, being a writer is a “monstrous” (24) condition, but it is also what equips him, more than anyone, to write about illness.

Daudet’s condition prevents him from working—neuropathy cripples his motor functions or he sporadically loses “all sense of everything” (66)—when all he wants is a “gentle return to work” (58) and to record what is happening within and around his body. Literature, in its most basic function of preserving memory, is all he has left. Soon, he will be gone and all that will remain of his body is his work. He clings to the act of recording, but obsesses with recording the ordinary, even mundane moments: “The hotel. The bell-board. The bath times,” he begins in an undated entry. Many begin like this, inserting the reader directly into a stream of consciousness, with no preamble or warning. The entry escalades in tone and urgency: “Solitude. Encroaching darkness” (105). Daudet’s book often reads like a miniature poem, one after another. Tiny odes of pain that strip him and the language of this entry of everything but what is absolutely necessary. Sounds and images of everyday life propel this entry forward, while Daudet’s body, nearly unmovable at this point, can do nothing else but listen to the world around him. Because of his book’s short, fragmentary form, he relies on specific features of verse composition in order to hyper-focus on creating images that are weaved together using theme tension and profound reflective thought, rather than the action of an exciting, able-bodied story. In another entry, also poetic in its stanza lineage and incantatory repetition of “farewell,” Daudet floats away in an “indistinct” haze to what we assume is the drug-induced “little house in the rue”:

> It’s all going… Darkness is gathering me into its arms.
> Farewell wife, children, family, the things of my heart…
> Farewell me, cherished me, now so hazy, so indistinct… (67)

So we might not know exactly where we are in time or place for several pages, but this displacement is purposeful, a replication of the disorientation that Daudet feels on a day-to-day basis. Unlike plotted prose, which frequently uses more complete logical or narrative structures, his work is created from the need to escape the logical, as well as express feelings in a tight, condensed manner. Daudet rarely describes his appearance or features about himself outside of his pain, but we find that he is most detailed and most visible when experiencing or marked by pain: “There are days, long days, when the only part of me that’s alive is my pain” (67). Or, “the way nurses talk,” he says, “‘That’s a lovely wound… Now this wound is really wonderful.’ You’d think they were talking about a flower” (67). He likens his wound to a flower, seeing both the beauty and pain of his suffering, but says there is only so much “moral and intellectual” growth that can come from this experience (79). There is nothing logical about his pain—where it emanates from, when it will begin or when it will subside—and so, too, reading his writing must mirror this experience.

Daudet is a writer-patient who experiences illness and then feels the crushing disappointment of not knowing if he is capable of sharing the realities of that illness—a duality which encapsulates his fear that writing about illness is beyond communication. It is a fear that manifests itself so deeply, that he constantly questions if he should shield his family from the full extent of his plight or if he should dilute the “harsh[ness]” of his book because:

> Poor humanity—you shouldn’t tell it everything. I shouldn’t inflict upon people what I’ve endured, this painful, all too self-aware end to my life. People should be treated as if they were sick; it’s a question of striking the right balance, of proper consideration; let’s make them love the doctor, rather than play the tough and brutal butcher (87).

The idea of treating healthy “people as if they were sick” speaks to the contradictions of his conditions and the enormous burden he feels as a sick person relying heavily upon his family. He takes this concern for others to saint-like proportions, seeking to protect the people around him from the true "horrors" of his pain, but this is impossible: everyone in his family takes on the burden of his disease in some way or another, from his wife to his father-in-law, to give him injections of morphine or care for him when he is incapacitated. For the most part, his family is only peripherally mentioned throughout the book, as if their presence (or more broadly, the presence of anyone) pale in comparison to his body's erosion. He attempts to tell his children "Long live Life!" while being "ripped apart by pain" (105), as he tries to claim this for this sake of their idealism—his future and living legacy—while not believing it himself. His pain is enfolded in layers of contradictions, from the way that he tries to simultaneously distance and pull his family closer into the experience, and for him, perhaps this contradiction of expression is the only kind of language that might suffice.

Narrative writing offers the chance to put back together a splintering body and position suffering in time and space, a means for identity construction and analysis. Daudet's catalog of pain expresses his struggle to be understood by his readers, but more holistically, reveals how his illness acts as a vehicle of love, of pain. Daudet's sentiment exposes the truth that anyone who has ever been sick can attest to, which is that illness is a solitary and scattering experience, suggesting that "personal stories of pain become flattened, generalized, and reduced to banalities by listeners" (Jurecic 46). The act of sharing his pain trivializes it, or at the very least, misrepresents it: "Are words actually any use to describe what pain (or passion, for that matter) really feels like? Words come only when everything is over, when things have calmed down. They refer only to memory, and are either powerless or untruthful" (53). He calls attention to the artificiality of reconstructing his experience, wondering if “words [are] any use” when trying to re-inhabit human emotion on the page. He is troubled by the value of writing about his illness, but his desire to keep writing and to keep recording his daily life answers this anxiety. Pain dictates the words he writes, even if he is in pain or in fear of pain. After all, why does it matter to him to express what it really feels like? Does that precision of language alleviate his pain? He is searching for something more, something intangible, whether it is kinship with others, his “dopplegangers in pain” (67), or in his written ability to bridge the gap between the healthy and sick.

At one point, Daudet hears clocks and church towers strike four o’clock over the course of ten minutes and wonders, “Why doesn’t everyone keep the same time? Essentially: our lives are so different from the other, that it makes sense for the disparity to be symbolized in this way” (52.) Everyone’s suffering differs, and as much as language and writing can fail reality, the reader also shares in this failure, believing that pain and trauma are tangible, or even equally understandable from person to person. Thus, Daudet’s efforts to record these impressions is uneasily tracked in how they may fall short or slip away from himself and the reader, and speaks to a greater discourse about the connection between the body, art, and illness. The heart of this project denounces closure and holds a pragmatic view of disease—“I do not believe I will get better,” he says, but even in the end, according to Julian Barnes’ footnotes, Daudet “talked about the project and even answered journalists’ questions about his progress,” still believing that there must be a way forward out of all of this. He often rejects his work or regrets the pressure his illness places on his family, but still believes in its potential as a series of impressions that engages with the limitations of language, of the body. There is not just one version of pain, or “no general theory about pain. Each patient discovers his own.” (46).

As Daudet finds, art is about the search for self, particularly at a juncture when the body becomes indistinguishable from its disease. In Daudet’s novel, the duality of pain and love hold the book together, but is he right about the limitations of language? Had he lived longer, perhaps his book would have taken a different shape or imagined other ways of replicating pain, but this tiny book is all we have. Daudet seems to answer many of his writerly anxieties by the book’s end: “I don’t care if my cannon-fire falls short, and the whole ship is falling apart. I’m going down fighting” (40), attesting to his belief in the narrative, in the good embedded within his own suffering, and in the attempt to fail and fail again.

# ILLNESS AND NARRATIVE DISTANCE

When it comes to writing illness, our bodies are contested, questioned, consumed, and often, ignored. Illness is chaotic, disorienting, and confusing, an experience that suspends how a body typically behaves or feels. Writing is supposed to be organized, meaningful, and understandable, the opposite of the experience of illness. But without language, how can experience be shared? Without language, how can community be formed? Lorde's *The Cancer Journals* views her cancer experiences through a feminist lens and contests Daudet's fears about the inadequacies of language when writing about illness, instead insisting that at the risk of misinterpretation or confusion, she believes "over and over again that what is most important to [her] must be spoken, made verbal and shared" (17). If not heard, she believes that her pain is "wasted" (14) and that is unimaginable, perhaps even more so than death. Diagnosed with a malignant form of breast cancer in 1978 and liver cancer in 1992, she uses both emotional and intellectual affects in her personal narrative to ensure her work has political implications beyond her in time and space.

Lisa Diedrich, in *Treatments: Language, Politics, and the Culture of Illness*, argues that writers have engaged with health and well-being in memoirs "as a form of subjectification, a practice in which we consider our relationship to ourselves, and illness narratives in particular as describing the cultivation of a self in relation to itself and to others, healthy, ill, and in-between" (25). Vulnerability and reconstruction of selfhood are at the heart of Lorde's work. Lorde becomes what Diedrich calls the "politicized patient" (26), a new era in illness literature in the 1980's where patients and writers began to "challenge the structures and structuring of illness from the patient's side of the doctor patient binary" to "present affective histories that are attentive to the rhetorics and practices of politics (27). This shift in illness narratives, fueled by a growing distrust in medical institutions, helped to circulate knowledge outside of the medical establishment and, as these narratives gained national traction, offered the patient's qualitative experience with disease as a viable alternative of scrutinizing the meaning and crisis of illness in a critical way.

This emergent politicization is also present in Susan Sontag's 1978 *Illness as Metaphor*, but the shared goal of normalizing and intellectualizing disease manifests itself very differently in her writing. *Illness as Metaphor* seeks to critique metaphors that formed surrounding cancer, but critics often cite the opening image of her book—a metaphor, of course:

> Illness is the night - side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (1978, 3)

We all hold "dual citizenship," she points out, describing illness as a destination that we find, as everyone inevitably discovers, that we were here all along. Illness, once again, becomes a place of exile or despair. Later, she criticizes the medical establishment's reference to themselves in a militarized capacity, "fighting cancer." In these military metaphors, the physician is the hero and the patient is supposed to wage war against herself, and becomes the battleground and the soldiers and the hostages. To vanish or vanquish. If this is war, then is the patient the winner or the loser? Is there a right or wrong way to be sick or to suffer? To metaphor or not?

In Sontag's essay we find a single-minded determination, without nuance or counterpoint, to exorcise all unwanted metaphors. Most of her book is preoccupied with the "encumbered" metaphorical use of tuberculosis in the 19th century and cancer in the 20th century, arguing how potent and misleading illness metaphors and figures are through examples of classic and modern literature: "Novalis, in an entry written around 1798 for his encyclopedia project, defines cancer, along with gangrene, as 'full-fledged parasites—they grow, are engendered, engender, have their structure, secrete, eat.' Cancer is a demonic pregnancy" (13-14). Metaphors like this, she argues, abstract the disease and blur the line between patient and illness. Her zeal to maintain literary distance holds her work together, from case studies on TB to the descriptions of cancer and TB and AIDS—"the agonies that cannot be romanticized" (36). While diseases like tuberculosis hollow us out, cancer is one of excess. Cancer is synonymous with malevolence and "barbarianism," an illness experience with no redeeming value, while tuberculosis is romanticized with connotations of mystique, thought to embody the superior "melancholy character": sensitive, creative, frail; in essence, the melancholy of the Romantics such as Keats and Shelley, who both suffered from the disease but consoled themselves in the knowledge that "this consumption is a disease particularly fond of people who write such good verses…" (32).

According to Sontag, a disease is a disease is a disease—not some evil character or lawless land—but in her efforts to reject these punitive metaphors, does she lose sight of herself? Does de-mystifying disease and its romantic conjectures mean expunging the brutality and grit of one's experiences altogether? Why strip illness of any and all symbolic meaning? Chemotherapy, for example, is a type of cancer treatment comprised of poisons meant to kill cells. The hope is to kill the malignant cells without killing you. Sontag writes, "Treatment aims to 'kill' cells…" (65), but puts "kill" into quotation marks, as if this is symbolic. Mechlorethamine, a derivative of nitrogen mustard, is used in lymphoma treatment to kill cells. These drugs do not have the ability to differentiate between healthy and cancerous cells, so everything in the body is obliterated. When cancer metastasizes, it is actively colonizing other parts of the body, taking the best parts about our anatomy—the parts that make our bodies tick—and turn us against ourselves. These are not metaphors.

But the resentment is still there: the language of warfare and cancer puts the patient in the middle of a "fight" or "crusade" against this "killer" disease, and whether or not she wins or loses, the very words that describe this experience make her a victim (57). People devise puzzling, but well-intentioned ways of pairing cancer with strength that confuse or harm more than help: *You're a fighter*, a friend of my mom's wrote to me during my chemotherapy treatments, with a $100 bill enclosed. *Give it hell*, former president Barack Obama wrote to his colleague John McCain when diagnosed with brain cancer.

Generally, people do not know what to say, and so they rely on trite metaphors or moralistic meanings that "unwittingly" cause patients to feel as though they deserve this or worse, have any control over their outcome. The point is to temper or even completely re-evaluate the ways in which we discuss illness: "I discovered that many patients… are embarrassed about being sick," Sontag observed. "The doctors also treated the cancer as if it were something more than illness: It wasn't like having a heart attack… there was something taboo about it" (101). The heart of this essay lies in its desire to instruct the public and to not let language—specifically the discourses of others—to determine her thinking about cancer. Even when given a poor prognosis with little treatment options available, she pushes forward with the most toxic (and experimental) of treatments, "determined to live no matter how terrible her suffering."[2] She does not let the discourses of others determine her own thinking.

As Sontag argued, "conventions of treating cancer as no mere disease but a demonic enemy make it not just a lethal disease but a shameful one" (102), and this shameful portrayal would have the most serious and negative consequences on the psychological and social anguish of patients diagnosed with the disease. D.H. Lawrence, for example, called masturbation "the deepest and most dangerous cancer of our civilization" while Hitler attempted to justify genocide and violence against the Jewish population by likening them to a "cancer that must be excised" (82). Regardless of how these illnesses are viewed, their symbolic meanings signify social and moral and political corruption. In the concluding paragraph of *Illness as Metaphor*, she suggests that the stigmatization of the ill reveal a deeper, systemic problem of society:

> But at that time perhaps nobody will want any longer to compare anything awful to cancer, since the interest of the metaphor is precisely that it refers to a disease

---

[2] https://www.nytimes.com/2005/12/04/magazine/illness-as-more-than-metaphor.html

> so overlaid with mystification, so charged with the fantasy of inescapable fatality. Our views about cancer, and the metaphors we have imposed on it, are so much a vehicle for the large insufficiencies of this culture, for our reckless improvident responses to our real "problems of growth," for our inability to construct an advanced industrial society which properly regulates consumption, and for our justified fears of the increasingly violent course of history (87).

Sontag treats the metaphor as if it is the enemy, more so than even the diseases or thoughtless perpetuators (i.e. doctors, strangers, friends and family and caregivers of patients) of trite expressions. However, in this final moment, she seems to reflect upon this and instead challenges the "vehicle" of fear rather than the fear itself, realizing that we, as a society, impose these metaphors of cancer on ourselves, on the people around us. "Of course, one cannot think without metaphors," she later clarifies in *AIDS and its Metaphors* (93). Metaphors have not distorted the fact of cancer, but rather cancer as metaphor reflects—"vividly," she adds—symptoms of larger issues, or "insufficiencies of our culture." Even still, "that does not mean there aren't some metaphors we might as well abstain from or try to retire" (93).

In *Illness as Metaphor*, Sontag rarely uses "I" and "cancer" in the same breath, leaving it to the reader to find the connection between her and the disease she dies of in 2004. Though this essay is told from the first person, Sontag does not broach any personal details, despite that getting sick is what made her think about sickness in the first place. Ten years after the publication of *Illness as Metaphor*, Sontag writes, "I didn't think it would be useful—and I wanted to be useful—to tell yet one more story in the first person of how someone learned that she or he had cancer, wept, struggled, was comforted, suffered, took courage … though mine was also that story. A narrative, it seemed to me, would be less useful than an idea" (*AIDS and Its Metaphors* 101). The underlying contempt for "yet *one* more story in the first person" (emphasis mine) reveals more about her repression of feeling, of the absence of terror and despair in the text of *Illness as Metaphor* than she'd ever let on. David Rieff writes, "So terrified of death that she could not bear to speak of it, my mother was also obsessed with it."[3]

During two and half years of chemotherapy treatment, she barely mentions her cancer. In February 1976, well into her treatment, she says in her published journals: "…I need a mental gym," and four months later (and we know this is related to her breast cancer treatment): "Love affairs with their energy + hope"—a pause in the entries held together by the stagnation of cancer—"When I can write letters, then…" There is heaviness in the sparse prose, a weight that hangs on the ellipses in both fragments, as if we are entering mid-stream into an experience and being pulled out prematurely. Before she can articulate her fear or despair or anger, she stops herself, and instead allows the bleakness of the white space hold that emotion. She allows for the structure of the journal to resonate in a way that words cannot. "Write aphoristically," she writes later in 1976 of *Illness as Metaphor* (410). She deals restlessly with the self, but ultimately does not permit space for the "I" in her book on her illness, despite that some kind of narrative gives form to her ideas, doesn't it? She considers form again in 1965:

> Form has to be organic to the material. The letter-form of [Algernon Swinburne's *Love's Cross-Currents* is the story, not just Swinburne's idea of putting the story in

---

[3] https://www.theguardian.com/books/2008/may/18/society

> epistolary form. The story *is* the idea that this woman is so powerful, so forceful that, merely by letters and with little face-to-face contact, she can manipulate people's lives, prevent lovers from eloping. The story *is* Lady Midhurt's rhetoric—a rhetoric so seductive and compelling in its meanness, its intelligence, its accuracy, its suppleness, that she can manipulate at a *distance*.
>
> (*As Consciousness is Harnessed to Flesh: Journals and Notebooks* 67)

She rejects sentimentality and emotion in favor of concision and accuracy, writing her book with a self-described "evangelical zeal as well as anxiety" (101), not knowing how much time or space she has left. She seeks to separate herself from what she views as an overly emotional, personal narrative of illness but does so in a way that acts as a coping mechanism rather than dismissal or actual contempt, wanting to stay close to what is most effective and truthful in coping with disease, rather than what may be romantic or poignant. As evidenced, "truth" can be construed in vastly different ways.

# ILLNESS AND VISIBILITY: WRITING THE WAY BACK TO SELFHOOD

The memoir is a kind of life writing that can be seen as self-indulgent or even manipulative, a product of Western narcissism or Enlightenment rationality that puts the individual at the center of thought. Zadie Smith writes that she finds the first-person form "laborious and stressful"[4] and avoids it at all costs—often resorting to *we* as a way of obscuring herself—a perception that began to change for her once she arrived in America. Now, all she sees is the "I" littered throughout her writing. Sarah Manguso, on the other hand, who has kept a journal for over twenty-five years, has developed her own short-hand when writing, cutting verbosity when possible and dropping the personal pronoun from her prose altogether. The personal pronoun, she says, feels like "a drag," as if she is less tethered to the "I" with the passage of time.[5] Though she writes extensively about the self—losing no sense of interiority or production with her compulsive compression—this seemingly trivial syntax choice elevates daily events to the self, makes life the subject. "Narrative," she says, "is not a mode that has ever come easily to me." In *Ongoingness: The End of a Diary*, Manguso's meticulous diary keeping becomes her way of dealing with her pre-occupation with mortality and memory and time. As is the case with Sontag, her journals are a place of self-creation, where she is preoccupied with the desire to write and to live. At one point, she contemplates what it is that makes her

---

[4] Smith, Zadie. "Life Writing." Rookie Magazine, 10 Sept. 2015, www.rookiemag.com/2015/02/life-writing/.

[5] Beck, Julie. "When Diary-Keeping Gets in the Way of Living." *The Atlantic*, Atlantic Media Company, 27 Feb. 2015, www.theatlantic.com/health/archive/2015/02/when-diary-keeping-gets-in-the-way-of-living/386321/.

feel alive: “Who, what do I get a boost from?” she replies in a moment of vulnerability. “Language, first of all.”

Lorde, wary of Sontag’s call to depersonalize narratives of illness, is unafraid to use any and all emotional, literary, and intellectual resources to get her point across, which is that both political action and cultural critique are necessary if women can begin to resist dominant discourses of prosthesis, silence, and invisibility towards breast cancer. In doctors’ offices, Lorde feels powerless when confronted with her own mortality and uncertainty of whether her initial tumor is benign or malignant, and during this period of uncertainty, she reflects upon how the complexities of her identity is tied her work: “I have cancer. I am a black feminist poet, how am I going to do this now?” she asks (28). This is her second time of facing the possibility of cancer (having undergone a negative biopsy a year earlier), and while she feels the same dread of uncertainty, she exhibits more control over her reaction, having lost the “excitement of a brand new experience” (26). In her frigid recovery room, she yells and calls out for blankets, for human compassion and interaction, but no one hears her, no one comes. No one is listening. It is as if the sterility and insensitivity of the hospital leech heat and warmth from her body, and it is only when her female friends bring “coats to pile on her bed and then a comforter and blankets because the hospital had no spare blankets” (27) that her loneliness is assuaged.

Lorde likens her loneliness and illness to darkness and the cold, while female community and communication and connection bring her “delicious” (27) warmth and light, inciting a self-possessed rage in her “to do whatever was necessary to accomplish living” (32). Medicine and surgery temporarily halt the growth of cancer, but it is ultimately up to her to save her own life and determine the quality and authenticity of that life. “Growing up Fat Black Female and almost blind in America requires so much surviving that you have to learn from it or die,” she writes, and so this is yet another milestone of survival for Lorde. Her loss of her breast is only another trial that reminds her “that survival is only part of the task. The other part is teaching” (40). Though this is only a microcosm of how her illness sharpened and then became synonymous with her self-determination, each aspect of Lorde’s medical crisis represents how she seeks to liberate both herself and her readers from the confines of silence and utilize the female body’s perceived “weaknesses” as a means of expanding their own power and knowing. Thus, the rebellious ideology of her book is as much tied to her identity as it is to the narrative structure itself.

With the surgical removal of her cancerous, yet “beloved [right] breast” (33)—a part of her that supposedly defines her identity as a woman, as how a typically *attractive* woman is seen—she must reconstruct her very understanding of her “new body, new time span, possible early death” (38). Integral to this reconstruction is her writing and the ways in which her illness shapes how she confronts her one-breasted self. Lorde’s post-mastectomy body cannot help but inspire metaphor-making, calling herself an “Amazon warrior” as a way of reclaiming her body and strength and experience. She owns this proudly, wondering often how Amazon warriors might behave when vulnerable, or noting how “Amazon warriors of Dahomey have their right breasts cut off to make themselves more effective archers” (34). Many of these facts lend themselves to her mission, ripe for meaning-making. She embraces the personal, rather than the distance, and writes to accept having cancer and having lost a breast, and the implications of this new reality for her present and future life.

Lorde's collection of journal entries are often chronologically dated and contextualized around post-mastectomy reflections, but they are layered to reveal Lorde's physical and spiritual condition as the book progresses. The entries compound one upon another, entreating the reader to not forget that these curated entries reveal as much about the pattern of disease as they do about the pattern of language. The process of recovery is ongoing and uncertain. After her surgery, she endures a crucial period of reflection in which she feels as though she is "drugged and vulnerable and only able to record, not react" (40). She mourns her body's physical and emotional losses, but acknowledges that her fears are what strengthen her resolve to live and to fight. In the following journal entry, she lists her post-mastectomy pain and daily worries, especially in light of how disruptive her disease is to her work:

> "I am often afraid to this day, but even more so angry of having to be afraid, of having to spend so much of my energies, interrupting my work, simply upon fear and worry. Does my incomplete gall bladder series mean I have cancer of the gall bladder? Is my complexion growing yellow again like it did last year, a sure sign, I believe, of the malignant process? I resent time and weakening effect of these concerns—they feel as if they are available now for diversion in much the same way the FBI lies are available for diversion, the purpose being to sway us from our appointed and self-chosen paths of action." (54)

She asks a series of questions designed to highlight how her fears, like her cancer, grow exponentially with time, without her even realizing it. The running flow of this sentence mirrors the human mind, haunted by the disruptive and distracting nature of questions that cannot help but to be asked. We are placed in direct contact with her private thoughts from the onset of the passage: *I am often afraid to this day*, but she conditions this statement with anger that we sense building with each moment and thought of fear that "interrupts" her writerly goals. The why and when of these worries are uncontrollable. Through this process of elimination (i.e., is this cancer? or this?), Lorde attempts to control the narrative of her own body. She does not want these "diversions" to sway her from her goals, but these diversions—as convoluted or irrational as they may be (jumping from gall bladder to the FBI)—are not within her control, and she must accept that these insecurities and fears are part of her new "normal." These journal entries are central to the idea that identity is not static and crystallized—and suggest, instead, the myriad ways in which women of color have sought to articulate, confound, obscure, and explicate the body in their art.

"Shall I unlearn that tongue in which my curse was written?" Lorde asks, as illness threatens her sense of self, while narrative, even in its disjointed format, helps her to write her way back to visibility. In this journal entry, she is surrounded by "ugly images of women," distorted for the purposes of male art. Everywhere she looks, she is surrounded by loud contradictions and cannot help but question the efficacy of her own culture's language. Lorde's question underscores the relationship between identity and illness, to reject her disease is to reject her own body. The very tongue and language that fails her is also her only means of verbalizing her body's loss, and she urges her readers to find their tongue, their voices:

> "What are the words you do not yet have? What do you need to say? What are the tyrannies you swallow day by day and attempt to make your own, until you will sicken and die of them, still in silence. Perhaps for some of you here today, I am the face of one of your fears. Because I am a woman, because I am black, because I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?" (21)

She experiences another kind of pain, one borne from her silences. To her, silence is the equivalent of death, and she references "tyrannies" that once rendered her weak, now used as her strength. She entreats women to take up arms against silence, against the systems that seek to victimize and mitigate women, particularly when it comes to how they must cope with the after math of cancer. At first, she catalogues her identity into a contained and structured list—"I am a woman," "I am black," "I am myself,"—but she intentionally unravels her own identity into a breathless, stream of consciousness: "black woman warrior poet doing my work." She proclaims that she is "doing her job" by taking an active role to speak up for herself and others, and challenges other women to do their part as well. She connects her identity to that of a "warrior," and her prose reflects her urgent desire to reclaim her power in the face of loss and pain.

> "If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness. By accepting the mask of prosthesis, one-breasted women proclaim ourselves as insufficients dependent upon pretense. We reinforce our own isolation and invisibility from each other, as well as the false complacency of a society, which would rather not face the results of its own insanities. In addition, we withhold that visibility and support from one another which is such an aid to perspective and self-acceptance. Surrounded by other women day by day, all of whom appear to have two breasts, it is very difficult sometimes to remember that I AM NOT ALONE. Yet once I face death as a life process, what is there possibly left for me to fear? Who can ever really have power over me again?" (63)

She acknowledges the fear of visibility and the vulnerability that comes from such public exposure: "On the cause of silence, each one of us draws her own fear– fear of contempt, of censure, or some judgment, or recognition, of challenge, of annihilation. But most of all, I think, we fear the visibility without which we also cannot truly live" (22). Confronting this fear, though, represents a vital source of power. Lorde echoes bell hook's concept of "talking back" (1989) by discussing the need to "move from silence into speech" (9), an essential part of beginning the dialogue when it comes to illness.

The topic of reconstruction, as it applies to her breasts, opens a door for a feminist discussion about the expectations and ideals for women and their bodies. Lorde "talks back" to the dominant narrative that tells women they must cope with their disease in a certain way. In her eyes, to remain silent is to remain powerless: “A mastectomy is not a guilt act that must be hidden in order for me to regain acceptance or protect the sensibilities of others. Pretense has never brought about lasting change or progress” (67). By choosing to have her breast excised, that is, by choosing life over death, she begins a new process that allows her to “become a more whole person” (56). Lorde renders the excision of her breasts with both emotion and intellect, wanting both the reader and herself to see the state of her body, in its altered form, without any shrouding or masking. After Lorde’s breast cancer surgery, she refuses to have breast prosthesis because she considers it at odds with her identity as a woman and survivor. Despite the fact that “a kindly woman” comes bearing “a soft sleep bra and a wad of lambswool pressed into a pale pink breast-shaped pad,” she refuses to cower under the societal expectations that ask her to render her experience invisible, unseen. The nurse asks her to do so, if only for the morale of other patients, not understanding that her request is as violent as the excision itself.

Ultimately, she wants to “affirm” this difference that the loss of her breasts raises because she has “lived it and survived it” and believes that this is the fist step to “translat[ing] the silence surrounding breast cancer into language and action,” and thus, bringing these women back from obscurity (63). Deviation from the ideal female form is the point. She redefines what a book about illness can look like—chronological at one moment or sampling poems in the next, emphasizing that this book, like her body, is a reconstruction of selfhood. Rather than feeling trapped inside her disease, she reclaims some of her agency by partnering with her illness against dominant discourses that would silence her because she chooses to speak her truth.

# CONCLUSION

Every morning, I wake up and look at myself in the mirror, trace the shape of my chest's scar teeth left behind by the chemotherapy port they slid under the skin. I see this wound every day. I'm still learning how to write about my wounds. How do we write and talk about these wounds, our illnesses, without idealizing or exaggerating them?

For three writers-turned-patients, Daudet, Sontag, and Lorde, their experiences with illness and suffering catalyzed their writing and philosophical ideations, moving each of them to write about how to process illness, and in their case, the act of surviving and creating is indistinguishable from their craft. But to claim that suffering is generative falls short does precisely what Sontag argues against, which is to elevate it to a mystical level and abstract the pain of the person behind the illness, the sufferer. However, in her attempts to humanize or de-mystify illness on a broad scale, she avoids facing what is a deeply personal book stemming from her inability to reconcile her body's fragility with her fear of extinction. Dauduet, on the other hand, searched endlessly for the right words, to articulate his body's relationship to language. Lorde's approach to her illness combines the personal and political and historical, believing in the relevance and importance of the illness memoir, for both herself and her healthy and sick readers: "May these words serve as encouragement for other women to speak and act out of our experiences with cancer and with other threats of death, for silence has never brought us anything of worth" (8). With the possibility of "the richness of living for all women," creating a necessary bridge between the healthy and sick becomes imperative now more than ever. She uses the essay form and excerpts from her journal entries in order to engage more readily with the reader, asking us to "participate in the non-narrative, nonliterary experience of the text."[6] Each of these books urges the reader to consider how experience and memory and trauma translate into theme and structure. There is no right or wrong way to write about illness, but

Writing shapes us even as we try to find ways to tell a story that feel "organic" or true to that experience. In the essay "Writing With and Through Pain,"[7] Sonya Huber describes the debilitating pain and "head-fog" of rheumatoid disease that halts her writing altogether, forcing her to come to terms with her body's altered state. A fog that is dense and uncertain and she cannot escape, so she forces out a few words when she can and tries to "remind [her]self not to be scared of the pause. Out of the silent fog, another thought will emerge." It is up to us to write and un-write and make language and silence collaborate, to fail and muck in the articulation of human emotion.

E.M. Cioran, another writer-turned-patient, wrote in *On the Heights of Despair*: "Compared to the refined culture of forms and frames, which mask everything, the lyrical mode is utterly barbarian in its expression. Its value resides precisely in its savage quality: blood, sincerity, and fire." The idea of becoming a barbarian, that is, to strip the prose and person of everything and reduce your behavior and thoughts to the most essential, fundamental form of self, perhaps best echoes the intellectual and spiritual agony of sickness. Sontag calls cancer the "barbarian" within, so perhaps it does take illness for us to consider our best and worst selves. If I must become a barbarian in language, in survival, to articulate and make sense of my experiences, then so be it. The difficulty in writing about illness, or any trauma for that matter, lies in the nearly

---

[6] Morrison, Toni. "Memory, Creation, and Writing." Thought, vol. 59, no. 4, 1984, pp. 385–390.

[7] https://lithub.com/writing-with-and-through-pain/

impossible task to give voice to the unspeakable, and so I must find other ways to portray its inevitability and intensity. Language is not enough, and yet it is the only way to ensure both illness and the patient do not vanish from public and private consciousness altogether.

# WORKS CITED

Beck, Julie. “When Diary-Keeping Gets in the Way of Living.” *The Atlantic*, Atlantic Media Company, 27 Feb. 2015, www.theatlantic.com/health/archive/2015/02/when-diary-keeping-gets-in-the-way-of-living/386321/.

Daudet, Alphonse. *In the Land of Pain*. Vintage Classics, 2018.

Diedrich, Lisa. *Treatments: Language, Politics, and the Culture of Illness*, University of Minnesota Press, 2007. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/washington/detail.action?docID=328375.

Jurecic, Ann. *Illness as Narrative*. University of Pittsburgh Press, 2012.

Lorde, Audre. *The Cancer Journals*. Aunt Lute Books, 2006.

Smith, Zadie. “Life Writing.” Rookie Magazine, 10 Sept. 2015, www.rookiemag.com/2015/02/life-writing/.

Sontag, Susan. *Illness as Metaphor*. Penguin Books, 2002.

Woolf, Virginia. *On Being Ill*. Martino Publishing, 2014.