

Sickness in Storytelling: The Effects of Chronic Illness on Memoir and the Author

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### Abstract

The thesis will be in two parts, research and creative. The first part will be a research-based paper exploring how the creation and content of memoir is influenced by authors with chronic illness, and the difficulties and unique perspective these authors bring to the craft of memoir will be investigated. The second part will be a short memoir that tells a personal story of living with an autoimmune disease, systemic lupus erythematosus. This first-person narrative will fluctuate between memories of personal experience, information on lupus, and self-reflection. Together, these parts will explore different aspects of chronic illness in memoir.

*Keywords:* chronic illness, memoir, creative nonfiction, author

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**Introduction**

A well-told story encapsulates an idea, an emotion, and a human experience. It bridges the gap between storyteller and audience, allowing both parties to temporarily share an experience. Stories, whether factual or fictional, influence people's lives. Nonfiction, especially, has a unique impact on its audience precisely because it is based in reality. In true-to-life stories the audience can learn from the author's past mistakes, share in joy and suffering, and empathize with the journey the writer undertakes. These stories are particularly powerful when the author deals with an intensely personal struggle: the loss of a loved one, a mental or physical illness, or a dysfunctional childhood. Stories with those kinds of topics require intense vulnerability on the part of both the writer and the reader, especially when it comes to writers with chronic illness. Memoirs are often about past events in a person's life, but chronic illness will never be a past event. Because of this, any closure that exists in the story of a person with chronic illness is not simply that of time. Chronic illness is, and always will be, a significant part of the author's life and so requires a different kind of vulnerability. Because of this difficulty, writers with chronic illness have both unique opportunities and unique difficulties when it comes to writing a memoir about their chronic illness. The level of vulnerability necessary for memoir that deals with chronic illness can be difficult to undertake because of the nature of chronic illness. The effects of chronic illness on an author are evident in memoir, but just as with any other memoir subject, the impact on the author and audience is powerful.

### Chronic Illness in Memoir

Like other forms of memoir, the chronic illness subset of creative nonfiction contains more than biography or a purely chronological narrative of history. Memoir holds special interest for an audience because it moves beyond an accumulation of well-presented facts to tell a more nuanced tale. While factual events make up the foundation of memoir, the underlying story communicates less about what happens to the author or narrator externally and more about what happens internally. Especially when writing about chronic illness, the author must focus less on the disease itself and more on the internal struggle that goes along with such issues. The reader watches a story unfold where “a really interesting, unpredictable mind struggl[es] to entangle and disentangle itself in a thorny problem, or even a frivolous problem that is made complex through engagement with a sophisticated mind” (Lopate 6). Writers of memoir must be willing to open themselves up to scrutiny by their readers, because the internal emotions associated with a memoir compel the audience just as much as the external facts. Mary Karr, author of *The Liars’ Club*, acknowledges the raw honesty necessary for writers telling their personal story: “memoir—with its single, intensely personal voice—wrestles with family issues in a way readers of late find compelling” (XIV). This also applies to writing about chronic illness issues. The “single, intensely personal voice” of a narrative about chronic illness has many of the same attributes as that of writing about family issues. Writers with chronic illness must also come to terms with the story they will share—not just the facts of their illness, but how they have been personally affected by their health issues. Accepting the betrayal of one’s own body requires a lot of vulnerability from the author,

which is what attracts the audience. It is this authorial struggle to be authentic, as well as the physical circumstances of a person's story, that draws readers to memoir about chronic illness.

When writing about chronic illness, a writer must balance the story of living with a disease with his or her personal story. Writers, whatever they create, draw from their own lives in order to ground their words in reality. Flannery O'Connor, a writer who suffered from systemic lupus erythematosus, gave this advice to aspiring writers: "The fact is that anybody who has survived his childhood has enough information about life to last him the rest of his days. If you can't make something out of a little experience, you probably won't be able to make it out of a lot. The writer's business is to contemplate experience, not to be merged in it" (O'Connor 84). Contemplating the experience of chronic illness requires a lot of self-reflection on the part of the author, who must find a balance between her story as a person and her story as a person with chronic illness. In her memoir *Furiously Happy*, author Jenny Lawson tackles the subjects of mental and physical illness through her struggles with rheumatoid arthritis and depression, among other conditions. Lawson allows the difficulties she has gone through to impact the way she writes and accepts these things as a normal part of her life without allowing her diseases to overshadow her (often humorous) story of personal growth. While chronic illness remains prevalent in her memoir, other aspects of her life, such as her dysfunctional family relationships, also contribute in major ways (Lawson 4). While some authors of chronic illness memoir deal with the illnesses themselves, others merely witness this struggle in the lives of others. Mitch Albom wrote a memoir about watching

his long-time professor and friend deal with Lou Gehrig's Disease in *Tuesdays with Morrie*. Through Alбом's recorded conversations with his old teacher, the reader learns about a man who must deal with illness and mortality through the disease and eventual death of his friend. Yet the book's focus is less on the disease itself and more on love, loss, and the influence a single person can have in the lives of those around them (Alбом 192). Memoir is a powerful tool, and writers who deal with chronic illness have a unique perspective on these diseases and therefore can provide a clear, personal depiction of how chronic illness affects so much more than just the physical body.

### **The Process and Methods of Writing Memoir**

Fiction and memoir differ greatly in many areas, but the one that affects writers the most is in the writing process and the building of the story because they cannot change the facts of their life or illness. With fiction, authors simply decide on a plot and characters, and they can manipulate their chosen story however they wish. However, when it comes to memoir, authors are bound by the truth of their own lives and, for writers with chronic illness, their own diseases. This changes the way a writer approaches her story, because rather than simply conjuring up a protagonist from thin air, "the writer needs to build herself into a character" (Lopate 17). The good thing about this is all the materials for a story already exist; the difficult part is that these facts cannot be altered to fit into a more pleasing or gripping narrative. Especially with chronic illness, there is rarely a resolution with the disease itself. Instead, the author must look internally to find the closure that the story needs. However, as with fiction, the presentation of the subject matter can change the entire meaning of a story: "good memoir writing employs literary

devices and craft found in fiction and prose writing, elements that enliven and quicken a story” (Mills 10). Though the life of a person with chronic illness may not include a miraculous healing or a life-changing medication, the story the author chooses to tell can still be powerful and inspiring. While the author of memoir must rely on facts for the foundation and general plot, the purpose and meaning of the story are still up to the writer. Though they cannot change the actual events that have happened in their life, authors must build the structure of their story in a way that brings meaning to their experiences.

### **The Influence of Memoir on the Writer and Reader**

The physical and mental effects of writing can be extra difficult for authors who deal with chronic illness. Writing a memoir requires a great deal of time and energy, and people with chronic illness tend to struggle with fatigue and exhaustion (Swain). Toward the end of her life, Flannery O’Connor was only able to write for an hour a day (Desmond). In dealing with her chronic illness, O’Connor was forced to pace herself in her writing, yet she continued to write for the remainder of her life despite her many difficulties. This is common among authors with chronic illness, who must struggle against their own bodies to be able to write. For author Nafissa Thompson-Spires, an author with endometriosis, writing is an important part of her life despite the difficulty of also dealing with a chronic illness: “It means something to me to be able to produce [writing] when [chronic illness] is daily trying to take me out” (Thompson-Spires). Aside from physical complications, the mental toll that writing a memoir has on the author is another difficulty for writers with chronic illness. Because chronic illness is such an



elusive category of illness, it is not well known or understood. This fear of vulnerability is common among all authors of memoir, but there is an additional burden for people who have chronic illness because of the many unknown factors of the diseases they deal with. Nafissa Thompson-Spires said writing about her chronic illness often prompts questions she does not know how to answer: “I fear these admissions will inspire intrusive biographical questions from friends and family, that I will become, involuntarily, some kind of mouthpiece for something before I am ready” (Thompson-Spires). Because of this, compelling memoirs about chronic illness can affect the way the author is perceived in real life, and it can also affect how people view the chronic illness the narrator deals with. While memoirs are supposed to focus on the individual within the story, they can also influence how readers view an entire category of people, such as chronic illness sufferers. This puts even more pressure on memoir writers because they must also be mindful of how they are portraying the disease they deal with. The mental and physical strain of writing a memoir takes a toll on writers with chronic illness, and they often feel additional pressure because of the connotations of their disease.

Writing about their chronic illness allows authors to channel their health issues into their work, bringing purpose to their struggles while enhancing the story they tell. Nafissa Thompson-Spires uses her chronic illness to fuel her writing and inspire her readers: “The other bright side of my pain is that I have all these stories to tell, and I’m telling them” (Thompson-Spires). A common writer’s maxim is to write what you know, and writers with chronic illness know their life and disease better than anybody else. Flannery O’Connor learned to use her experiences to better her writing: “[good writers]

have had our Fall. We have gone into the modern world with an inburnt knowledge of human limitations and with a sense of mystery which could not have developed in our first state of innocence” (O’Connor 59). The difficult experiences that O’Connor faced influenced the way she wrote and even thought about things, though she never actually wrote a memoir about chronic illness. Her stories were, often indirectly, influenced by her health struggles: “[O’Connor’s writing was] the vibrant, darkly comedic words of a woman whose mortality echoed in every ache and fever, whose daily life was subject to the whims of her malady” (McCoy). Rather than allowing her disease to suppress her writing, Flannery O’Connor used her illness to motivate and influence her in her writing. For authors with chronic illness, the influence their illness has on their writing can make their work more meaningful and help them to share their story in an effective way.

Chronic illness does not just affect one person, it affects everyone around them, which can add another level of difficulty to writing memoir. Whatever story a writer chooses to tell, it is not just the story of one person. No life is lived in a vacuum. Family members, friends, and even strangers are integral parts of everyone’s life, and a memoir writer with chronic illness is no exception. Sometimes the truths that memoir writers choose to tell hurt the people they write about, and while they must be mindful of that, they cannot guarantee their writing will not offend anyone: “complicating the dilemma is that one does not always know what will cause offense” (Lopate 83). So, while writers must be conscientious toward the people they write about, there is no guarantee that their descriptions will be inoffensive to everyone. For writers with chronic illness, this can include honesty about how other people viewed their illness or how they were treated

because of it. There are two possible outcomes when writers talk about the people who are a part of their life: “writing about one’s family or intimates can be an aggressive, vindictive act, but it can also be a way of communicating something to loved ones you never could before” (Lopate 84). Writing honestly about other people in a memoir is a double-edged sword: sometimes it hurts, but sometimes it helps. Though writing about other people is a task that requires some delicacy, it can also provide great rewards.

Making mistakes is a part of being human, and often these mistakes are a vital part of the larger story of a person’s life which can be used to repair broken relationships. Writers with chronic illness have the opportunity to use memoir to address issues about the treatment of people with chronic illness, but they must also be conscientious of those they write about.

The act of writing a memoir forces the author to mull over his own experiences, which can change the way a person looks at his own life. Many memoir writers with chronic illness have gone through terrible experiences, but the act of writing and publishing these details can often be cathartic for the author. From chronic illness to family issues, viewing these negative details as part of an overarching story changes the way authors look at their own life. For Mary Karr, the publishing of her memoir changed the way both she and her family felt about their dysfunctional experiences which Karr had shared with the world: “as certain facts that had once scalded all our insides and almost decimated our clan got broadcast a thousand times, we got oddly used to them” (Karr XII). Raw honesty is appreciated in the world of memoir, because readers crave authenticity. The audience’s desire for genuineness often leads memoir writers in search

of “some meaningful moment that somehow shaped the writer's life” (Mills 6). For writers with chronic illness, that meaningful moment is often attached to their illness in some way. Writing about very personal or sometimes sensitive subjects such as chronic illness allows writers to process their experiences and can also help to bring peace to painful memories.

Reading a memoir can change the way the reader views his or her life and the world around them, and for people with chronic illness, reading about another person's experiences can bring hope and understanding for their own disease. Memoir has grown in interest in recent years, perhaps because of a desire for truth and sincerity: “memoir has become the central form of the culture: not only the way stories are told, but the way arguments are put forth, products and properties marketed, ideas floated, acts justified, reputations constructed or salvaged. The sheer volume of memoirs is unprecedented” (Yagoda 28-29). People are searching for authenticity and shared experiences in a world where truth can be difficult to come by, and memoir can fill this gap for people with chronic illness by portraying these conditions in a personal and realistic way. While individual accounts are unique, the story of a person dealing with chronic illness resonates with many readers. Chronic illness is not an uncommon experience, since six out of 10 adults in the United States suffer from at least one chronic illness (“Chronic Diseases”). For authors who write about chronic illness, it means that many of the readers who pick up their book have some experience with chronic illness. For memoir author Porochista Khakpour, who suffers from Lyme Disease, writing about her illness allowed her to vocalize the struggles of Lyme Disease in a way that readers connected with.

During an interview, Khakpour spoke of the overwhelming response from readers who had gone through a similar experience: “People were reaching out to me from all over the world who were grateful for how I was writing about it. There weren’t a ton of people talking really candidly about Lyme. It felt like public service to share that story” (Rowe). The more genuine writers are about their illness or other struggles, the more their readers will relate to these written experiences: “creative nonfiction writers inform their readers by making the reading experience vivid, emotionally compelling, and enjoyable while sticking to the facts” (Cheney 2). Reading the right book at the right time can change a person’s life. If writers of memoir tell their stories well, they will have an impact on readers: “reading about simple day-to-day realities an author has experienced can help the reader understand that they are not alone. Such stories from our own lives may also serve as guideposts to later generations of our families” (Mills 2-3). Reading a memoir of chronic illness can bring hope to people who deal with similar issues, and it can inspire empathy for people who have never dealt with such a disease.

### **Human Experience and Memoir**

One of the reasons memoirs attract so much interest is because of the individuality of the human experience, whether through chronic illness, cultural upbringing, or other experiences. No two people can live the same life, and everyone has their own story to tell. When two or more people witness the same event, they will by necessity remember it differently, a phenomenon known as the Rashomon Effect (Davis et al. 66). When writing a biography or other strictly factual account, a purely objective point of view is necessary, but when it comes to memoir and writing down personal

experiences, the individual's story is what interests the reader: "An artist works outside the realm of strict logic. Simply knowing one's intention and then executing it does not make good art. Artists know this" (Saunders). Because every person cultivates his own experiences, writers are able to pull from those unique memories when they write a memoir. Whether or not the writer's condition is the main idea in the memoir, the story is about an individual experience: "the writer operates at a crossroads where time and place and eternity somehow meet. His problem is to find that location" (O'Connor 59).

Memoirists must rely on their own experiences and memories to create a unique story that will grab the attention of their intended audience and make for a one-of-a-kind tale, and writers with chronic illness can use this individuality to share their story with audiences through memoir.

Memoir about chronic illness combines the individual human experience with an issue that many readers experience on a daily basis, and its emotional value to readers and to authors cannot be quantified. Stories have always been an integral part of society, and memoir allows readers to empathize with the true stories of people around them.

With memoirs about chronic illness, readers can either feel understood by someone who has the same disease, or the reader will grow to understand someone else's experience with chronic illness. Memoir can have immense power over its audience: "the best nonfiction writers do not tell us how we should think about something, how we should feel about it, nor what emotions should be aroused. They simply present the concrete details" (Cheney 36). Through telling a personal story, memoir allows writers to influence their audience's way of thinking. For both the writer and the reader, memoir

provides an emotional connection unique to this form of writing: “[memoir creates] that mythic village of like-minded souls who bloom together by sharing old tales—the kind that fire you up and set you loose, the true kind” (Karr XVI). Memoir creates a culture and a world all its own, which both authors and readers inhabit. Though it is an extremely personal form of writing, memoir about chronic illness bonds people from all walks of life and creates connections between strangers which can have lasting impact.

### **Conclusion**

Memoir is more than just a story—it is a piece of someone’s life which the writer has chosen to share with everyone. An intimate yet public portrayal of someone’s personal experiences, memoir requires a great deal of vulnerability, especially for writers with chronic illness. However, the genuine nature of memoir draws people of all ages and walks of life toward this genre. Combining the power of good storytelling with the authority of real-life experiences has created a genre of stories that change the way people look at the world and chronic illness. Stories are meant to bring people closer together, and memoir about chronic illness does that in a distinctive way. Through the struggles the writer faces both physically and emotionally, the audience connects with them on a deep level. Memoir about chronic illness provides a way for authors who deal with different diseases to share their stories with an audience, which can change the way people look at the world and how they look at chronic illness. The following creative work “Relatively Normal” is an attempt to practically implement this research on the relationship between memoir and chronic illness as I use memoir to tell my story of living with a chronic illness, systemic lupus erythematosus.

## Relatively Normal

“You’re very brave,” the nurse commented as she snipped the single stitch from my shoulder where, two weeks ago, she had removed a dime-sized chunk of skin from my right arm.

Pulling and tugging, she chattered away about the six-foot-tall guy who came to the office last week and went through the same procedure.

“He cried like a little girl,” she whispered in mock secrecy.

I laughed to humor her. I’d been waiting for results for 14 days, and I’d been waiting for answers even longer. This was the least brave thing I’d done all week.

I wasn’t used to traipsing regularly through doctors’ offices—other than the time I had strep throat when I was about ten, my only interactions with doctors were yearly physicals. But I could barely get out of bed from fatigue, my head ached constantly, and any physical activity was now accompanied by pain.

I didn’t want to believe it, but something was wrong with me.

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When people talk about chronic illness, they tend to use the word “journey.” *This is my journey*, as though their disease had given them a road map. But instead of a straightforward path to follow, it feels more like a faulty GPS which keeps blurting “turn left” even though turning left would launch you straight off a cliff.

At first, I ignored the symptoms. The solitary red spot on my nose was “just acne” and the never-ending exhaustion could be a teenage growth spurt. But soon small red dots



spread over my face and down my arms like I'd walked through a forest of poison ivy. I stopped looking in mirrors, and my mother made a doctor's appointment for me.

After filling out my medical history over and over and spending hours in waiting rooms, I still knew nothing. Neither, apparently, did my doctors.

Eventually, my physician suggested a specialist, which is a doctor's way of passing off unsolvable problems to somebody with more degrees on their office wall. Two months after my first appointment, I made my way to the dermatologist, who decided to scoop out a bit of my upper arm in hopes it would tell her something I couldn't.

The skin around my stitch healed into the shape of a tiny four-leaf clover. As I sat in a strange doctor's office at the age of sixteen, I could barely distinguish it from the other red spots. Though the rest of the blotches on my skin eventually faded, I can still see the scar.

I sat on the examination table and waited for the dermatologist, picking at my fingernails and distracting myself by listening to the conversation between the nurse and my mother. Part of me hoped the doctor would have answers. Part of me was afraid to hear them.

My mother can, according to my father, sell ice cubes to an Eskimo, but even her conversation capabilities were coming to an end by the time the doctor entered.

A summer dress peeked out from under the dermatologist's white coat as Dr. Spears walked in. She looked rather like a hippie masquerading as a doctor, but her

manner was sharp and professional. She crossed one brightly-colored sneaker over the other and launched into her speech.

“The good news is, you’ll be able to live a relatively normal life,” Dr. Spears said, wrinkles creasing her mousy face as she smiled. “The bad news is you have something called Systemic Lupus Erythematosus.”

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Lupus is what’s known as an autoimmune disease. Basically, an organism’s cells can’t tell the difference between harmful bacteria and its own organs, so the immune system blindly attacks everything it can find.

Doctors can’t cure it, they can’t predict it, they can’t even categorize it. All they can do is check symptom lists and scale pain (“Does it hurt when your arm moves like this?”). The patients get an ever-lengthening list of prescriptions and the doctors pray to their science gods that one of those powdery white pills will help.

Thirty years ago, lupus was a death sentence. After diagnosis, the patient was given maybe ten years to live in symptom-ridden existence. Thanks to modern medicine, lupus has been upgraded to life imprisonment. On the bright side, it’s a less harsh sentence.

Unfortunately, lupus makes my life a bit more complicated. Organs, joints, muscles—anything is fair game for lupus. The disease can be controlled, but curing it is impossible.

My mother always said, “Normal is just a setting on the dryer.” I heard that particular platitude all my life, usually to comfort me for the teasing about my unnatural

obsession with reading or the lack of an invitation to *that* birthday party. It never really helped when I was little, and it doesn't help now, either. I've come to hate the phrase *relatively normal*. Relative to what? I've lost what normal feels like, and I don't know if I'll ever remember.

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Post-diagnosis, my life became one long hands-on experiment. No stone unturned, no diet untried, no vitamin unswallowed. I must have gone to 10 different doctors in that first year, and offices, waiting rooms, and blood tests blurred together in my mind.

"I can't eat this." I dropped a spoonful of acidic yellow mush back into the bowl with dismay. "It doesn't even look like tuna."

My mother nudged some all-natural rice crackers toward me. "It's not that bad. Just try it."

My mother was a huge advocate for experimental diets. She was hopeful (or desperate) enough to try almost anything if she thought it would help me. She had read online about the anti-inflammatory powers of turmeric and, convinced it would bring healing to my disease-wracked body, liberally added the spice to every meal we ate for several days.

I drew the line at mustard-colored tuna fish, but my mother was only convinced to forego the turmeric diet when I angrily pointed out that she had stained all the measuring cups a bright, unnatural yellow.

"I'm just trying to get you better," she whispered, tears in her eyes.

“I know,” I replied, squeezing her hands.

That was the first, and only, time I cried over tuna fish.

Amidst the near-weekly diet changes and constant suggestions (yoga, green tea, positive thinking) from well-meaning doctors, friends, and acquaintances, my mother bought me yet another cookbook. The author had lupus but claimed to be living a mostly symptom-free life. I opened the book eagerly, ready to learn her secrets and begin my own journey to success.

I never made it past the introduction.

Because of lupus, the author said, her entire life was different. She wore “lupus glasses” that changed the way she looked at the world. Everything she ate, did, or said was influenced by her lupus glasses. She was never without them.

I was devastated. Tears filled my eyes as I thought to myself, I will never be that way. I won't let lupus alter the way I think and talk and live my relatively normal life. I will be different.

I truly believed lupus wouldn't change me. I was wrong.

In the book *The Wonderful Wizard of Oz*, Dorothy visits the Emerald City. Before she enters, she must put on special glasses, which she cannot take off until she leaves. When Dorothy goes into the city, everything is beautiful and green.

What she doesn't know is the Emerald City is just like any other city. It's only the special glasses that make everything look special.

Every decision I make is impacted by my lupus, whether I realize it or not. I have to choose when to push myself and when to rest, or I risk my symptoms flaring up and

making me sicker. I live in terror of relapsing, of reverting back to where I was that first summer. And, more than once, I've come pretty close.

I cannot remove my lupus glasses. They distort everything around me. But instead of making my world a more beautiful place, I just kept seeing the same ugly picture.

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“Why do you always wear a hat?” Several curious eight-year-olds stared at me, and my already blotchy face felt like it was turning even redder.

I readjusted my Eagles baseball cap, which had turned a dusty green after several weeks in near-constant use. “I have to be very careful of the sun.”

The little boy nodded, satisfied, and began to poke the kid next to him, causing a chain reaction of smacking and squabbling which I was supposed to magically remedy.

Exhaustion, sunlight, and stress are to be avoided when one has lupus, and I'd chosen to live at a children's camp for eight weeks, where those three things were in abundant supply. It was terrible for my condition, but I'd given my word to the other counselors, and I was determined to stick it out to the end.

My official diagnosis had come halfway through my first week of camp counseling. My mother tried to convince me to come home for the rest of the week, but I needed to come back. I couldn't break my promise.

I could hear the campers singing over the crackle of the campfire. Hundreds of stars twinkled in the rural Pennsylvania sky as I walked back to my cabin, hurrying to make it back before lights out.

I crept into the empty cabin and cried. Hard. I had a diagnosis, but that meant very little to me. The doctor had buzzed through her list of terms so quickly I still wasn't even sure what kind of lupus I had. All I knew was it began with an E and I hated it.

High-pitched voices and crunching gravel announced the dismissal of the campfire talk. I hurried to clean myself up, said goodnight to my campers as they filed into the cabin, and laid down in bed. After the shuffling of sleeping bags went still, I tried, and failed, to stop the hot tears from coming again. I felt very small, and very alone.

I made it through my summer at camp—barely. I wore hats and sunscreen religiously, and every night I collapsed on my bed, too exhausted to stay up and talk with the other staff members. Hardly anyone asked about the rash on my face, but I still felt like people were staring.

About halfway through the summer, I got a package in my mailbox. The counselors boosted morale by giving secret gifts to one another throughout the week, and I was curious as to who had drawn my name this time.

I opened my package (well-covered in duct tape) and found inside it a floppy straw hat. The note with it said something along the lines of, "Thought this would be useful for you," along with lots of blue-sharpie X's, O's, and hearts.

Later that week, my fellow counselor Rachel came up to me. She, it turned out, had been my secret gift-giver.

"I hope you liked the hat," she said, smiling with excitement. Rachel was the most genuinely cheerful person I had ever met. "I saw it and I just knew it would be perfect for you."

Most friends my age were sympathetic but clueless about chronic illness. If I hadn't had one myself, I wouldn't have known much about it. But Rachel's aunt had lupus, so she knew sunlight was a major trigger for me. She later told me she bought me the hat so I would have something extra pretty to wear.

I wore it for most of the summer.

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The computer screen flared in the 1 a.m. darkness, dozens of tabs lined up, demanding my attention.

Symptoms. Cures. Life Expectancy. Difficulties. Quality of Life. The terms popped up automatically from my recent search history, but I kept typing, trying to find something new.

I was just learning how to navigate life as a senior in high school with a chronic illness. I had been diagnosed for less than a year, and my days mostly consisted of sitting listlessly on the couch, attempting to complete history or grammar, and dragging myself around to typical high school activities like class or play rehearsals, none of which I would forego because of my disease.

My doctors kept telling me how well I was doing ("Your numbers look great!"), but I still spent most of my nights lying in bed, too exhausted to sit up yet unable to close my eyes and go to sleep. Instead, I surfed the internet, desperate for answers—better answers.

Keywords buzzed in my brain, chasing probabilities and what-ifs around and around. I knew more about the inflammatory properties of food than any seventeen-year-

old should. I had become bilingual in blood test abbreviations and percentage numbers. I took more pills in 24 hours than most kids my age would take in a month.

I had tried ignoring lupus, then I tried obsessing over it. Neither worked. And so I lived my days with as much of a smile as I could manage and filled my journals with entries that mostly ended with “I hate this disease.”

I wished I could stop existing. My wish was not granted.

Doctors will talk to their patients about the physical symptoms of a chronic illness, but they rarely speak of the mental ball-and-chain that comes along with such a diagnosis. The weight of mortality that attaches itself to your condition. That’s something the patient finds on her own.

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“Can I watch?” My roommate Brittany looked over at me from her desk.

I shrugged. “Sure.”

I sat on my bed, a handful of pills in my palm, and swallowed them in one quick gulp. Brittany looked impressed and a little terrified.

“How do you do it?” She demanded.

“I’m just used to it I guess.” I went back to my homework.

Brittany smiled. “Cool.”

College had many new challenges, but my new roommates accommodated my drawerful of pills and syringes without question and lovingly referred to me as our hall’s “drug lord.” It was endearing in its own weird way.



At the end of my first semester, I returned home exhausted, sick, and in constant pain, yet somehow, I still managed to go back to school at the end of Christmas break. Though my days off were filled with doctor appointments and my blood tests kept coming back with spiking numbers, I was determined to keep going.

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“So, how are you feeling?” My least favorite question.

I glanced across the restaurant table at Kasey, trying to determine what kind of answer she wanted to hear and which one I wanted to give. As the sister of one of my best friends from high school, Kasey fell between the outer circle of acquaintance and the inner circle of close friend.

“You know, ups and downs.” I smiled, keeping the conversation light.

On the six-hour drive home the day before, I had stopped at a gas station for nearly an hour and slept in the driver’s seat, too exhausted to keep my eyes open. *Fine* felt utterly unreachable. But I was home for my friend’s wedding. The last thing I wanted to talk about was my health, or lack thereof.

“Overall I’m managing pretty well.” I launched quickly into a story of how busy I am, what classes I’m taking, anything to direct the conversation somewhere new. I didn’t want to even think about lupus at the bachelorette party.

Kasey laughed at the right moments, and I got my story over with as soon as possible.

“Well, you look great,” she said, smiling at me across the table.

I knew she meant it, which made me feel even guiltier for my white lies. The waiter came over to take our order, and our conversation shifted back to decorations for the upcoming wedding and the antics of Kasey's kids.

There are two categories of serious illnesses in the minds of most people: cancer and non-cancer. I'm dying at about the same rate as everyone else, and on the outside I look relatively normal, so most people assume that I am healthy, or at least that I am doing better. I can recall dozens of conversations that ended with "you look so good." And I guess I do. I just don't feel it.

But I don't really want to talk about lupus. I don't want to talk about the constant aching that can make my fingers shake when I try to open doors. I don't want to talk about how sometimes I open my mouth and nothing comes out because my mind has been scrubbed blank. I don't want to talk about the bloodwork, the exhaustion, the headaches.

Or maybe I do want to talk about lupus, but I won't. Because if I don't talk about it, I can pretend it doesn't exist.

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The first time I lost some of my hair I was 17, and as I held a fistful of broken strands, all I could think was *thank God my sister's wedding is already over*.

The hair around my temples thinned considerably over the next month, and for a year I avoided wearing my hair up so I could hide the bald spots.

The second time I began losing my hair I was 20 years old and extremely insecure about my shrinking ponytail. I had tried for a couple months to pretend I wasn't shedding

hair faster than I could regrow it, but it was no use. Not even headbands could hide the fact that the hair around my temples had nearly vanished.

Over Christmas, I went with my mother and my two sisters to a wig shop. Walking through the door felt like entering a foreign land. I didn't know where to look first, so I just slowly tailed my older sisters as they started pointing out what they liked.

I tried on short wigs and long wigs. I modeled red, brown, and blonde wigs, my sisters snapping pictures of their favorite styles and tucking in wispy flyaways.

Despite their encouragement ("You look so good with bangs!"), I couldn't bring myself to get one. I had lost at least a quarter of my hair, but wearing a wig felt wrong. Weak. They scratched my forehead and every style made my head look too big.

So I determined to wait it out. I was not about to be defeated by my own head, however bald it might become.

That resolve lasted for about two months.

Short spikes of new growth slowly grew in, but I still felt ugly. Vain and silly though it was, I hated seeing my straggly hair in the mirror and I was sick of arranging and rearranging my part to make the most of my thin hair.

I was home on spring break, and fighting with my hair didn't feel worth it anymore.

I looked at my mother, who had listened to me complain for the last half hour, and said, "Screw it, I'm cutting it all."

Unusual hairstyles were generally frowned upon by my parents, and my hair had never been shorter than chin length. But my mom looked at me and smiled.

“Go for it.”

Which is how I ended up at a hair salon, slightly enraged, ready to end my long-term relationship with long hair.

“Are you sure?” The stylist looked at the picture on my phone uncertainly.

“Absolutely,” I replied as she tucked the long cape over my arms.

I had no second thoughts as she buzzed the entire bottom half of my head, leaving the top half pixie-style.

The tickling razor felt ritualistically cleansing. All my negative thoughts from the past few months disappeared along with my hair.

The stylist turned me to face the mirror after she'd finished clipping the last bits, and I smiled wider than I had in months.

I touched the back of my head, running my fingers over the newly-buzzed hairs and welcomed the cold breeze on my unprotected scalp. I looked older.

With lupus, you cannot guarantee day-to-day outcomes. One morning you'll wake up fine, the next, you feel like you've been run over by a semi-truck in your sleep. With chronic illness, so few factors are in your control that you have to take advantage of those little things you still have mastery over.

Sitting in the barber's chair, I was surprised to find that I felt free. Totally in control.

I have never in my life received as many compliments as I did over that haircut. Strangers would tell me I looked beautiful as they passed by, my roommates screamed when I returned from spring break, and every time I looked in the mirror, I was smiling.

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Christmas had finally come. With my final year in college, senioritis had begun to hit hard, and that combined with the pure exhaustion lupus brings on made me appreciate a break from school more than usual.

My whole family—12 people, including my nephew and two nieces—had managed to gather together to do the two things necessary to celebrate Christmas properly: exchanging gifts and eating food.

As a college student, every second with my family was precious, but the combination of new medication and the nonstop celebration of the past couple of days had taken their toll on my body. It was barely 11 a.m. and I was exhausted.

I sat on the couch, desperate to be a part of things but unable to fully participate. I watched as my brother-in-law played trains with my nephew and my sister made pretend birthday cake with my niece.

My brother, baby girl in his arms, came over and plopped on the couch beside me.

“How are you doing, sis?” He asked as the baby drooled in his lap.

“I’m... alright.” I watched my niece chew on the corner of a still-wrapped gift. She was far more interested in gumming the red- and green-striped paper than in what lay inside the package.

“Are you really alright, or are you just saying that?” He gently tapped my knee, separating baby and mangled present with his other hand.

I had been able to push through the constant fatigue and the pain, the late nights and last-minute assignments. I had typed papers with hands trembling from arthritis, and

I had chopped all my hair off just to spite my disease. I'd even managed to ignore the well-intentioned murmurs ("Just a semester off, perhaps?") from doctors, friends, and the little voice in the back of my own brain.

But I could not ignore the concern in my brother's eyes. So, amidst the chattering of my siblings and the crashing of Lego trains, I told my brother all about the pain, the fatigue, and the new medication that wreaked havoc on my mind and my moods.

My brother is pretty much the poster child for the American Dream. He's got the job, the house, the kids. All that's missing is the white picket fence.

He's always pushed me to do better and done what he could to help me succeed. He's a problem-solver and a go-getter.

But instead of trying to fix my problems or offering a solution to what I was dealing with that day, he simply squeezed my hand and said, "Can I pray for you?"

That prayer changed nothing about my body. It didn't magically fix me, and I'm still sick. But it did something that platitudes and pills could not: it showed me that comfort comes from more than just a solution. Though my brother could not fix me, he still cared for me in the best way he knew how.

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When you're sick, you take pride in odd little accomplishments—little ways of getting around the limitations set up by chronic illness. *I took the stairs today. I didn't ask for an extension on my school project. I didn't flinch when I got blood drawn for the second time this month.*

My special point of pride? I had never been sent to the hospital because of lupus.

I kept that winning streak for nearly six years.

Two weeks into my final semester projects were piling up faster than I could keep track. But I was sleeping, I was eating, I even had a couple movie nights.

I was doing everything I was supposed to do.

When it started, the pain was barely noticeable. Amidst every other body part that hurt, a little extra tightness when I inhaled was the least of my problems.

“Are you okay?” my roommate glanced over at me.

“Totally. This cough is just hanging on.” I rubbed my chest a little and hoped I would be better in the morning.

But the second day was worse. The front of my chest felt wrapped in steel wire and after climbing three-and-a-half flights of stairs I paused, in tears and unable to make the last few steps.

I possess a substantial amount of willpower, often to my own detriment. At the age of eight, I spent four hours in the Emergency Room after I tried to beat my sixteen-year-old brother in a bicycle race. I emerged with five stitches on my chin and the pride of knowing I had almost defeated him.

The problem with chronic pain is that you never know when enough is enough. You get so used to aching and tenderness that any new symptom only makes you think *here we go again*.

So I wasn't concerned when the thought *this must be what a heart attack feels like* crossed my mind once. But then it happened again. And again.

A phone call later my doctor insisted I go to the Emergency Room. Which is how I ended up spending my Friday night typing up a school assignment on my phone as I sat in a vinyl waiting room chair, an IV port in my arm.

“Your numbers are a little high,” the doctor said, looking over my charts. “We just want to make sure it isn’t something more serious.”

I nodded, consciously ignoring the nurse trying (and failing) to thread a needle through the vein in my left arm.

“On a scale of 1 to 10, how bad is your pain?” The doctor looked at me expectantly, pen poised to circle the magic number.

“Maybe a 4?” I finally turned to look at the nurse still fishing for a viable vein. “My other arm might work better.”

An EKG and a CT scan later, they told me I wasn’t dying. It was just lupus. I was sent home with strict orders to rest and take a lot of ibuprofen.

With chronic illness, it’s never just the one disease. The inflammation spreads everywhere in your body, causing all kinds of secondary problems, which means more pain, more medication, and more doctor visits.

Sometimes, the life of Dorothy in *The Wonderful Wizard of Oz* looks pretty great. Sure, she gets chased by an evil green witch, but how wonderful it would be to click my heels and wish my lupus away.

Everyone wants to be the exception. The walking miracle who astounds doctors everywhere. We all want magic shoes.



But no sparkly footwear will siphon the harmful cells from my body, and no magic wand can make me well. Some days I accept that, and others I still get sick to my stomach just thinking about it.

I was discharged from the hospital at 9 o'clock at night, and when I got back, my friends were waiting for me. Jack, who had sat in the hospital waiting room for four hours, and my roommate Julie guided me inside where my friends Max and Alison had helped prepare a (very late) dinner.

They gathered around me expectantly.

“Are you alright?” Max asked uncertainly.

I was emotionally and physically exhausted, I couldn't remember the last meal I'd eaten, and my inner elbow felt like a well-used pincushion. But I was still standing, and right now, that felt pretty good.

“I will be,” I said. And I meant it.

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