## A Place of My Own:

Making Space for the Experience of Chronic Illness

in Modern Literature

by Megan Pietz

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Francesa Royster, English

Kathleen Rooney, English

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### **Original Proposal**

The topic of my thesis is the effects of a chronic illness on the life of an average college student with a focus on the female experience. Specifically, this thesis project will look at my personal experience with chronic illness and detail the ways that my illness and its repercussions have changed what one would deem an expected or normal college experience. This topic will be explored through a combination of research and creative work with the ultimate product a chapbook consisting of fifteen to twenty poems that reflect on my experience as a chronically ill, female college student.

This chapbook will be informed by the reading of multiple texts by female authors and or female-driven texts. While there are not easily identified chief authorities in the field, the research will span both fiction and non-fiction texts, poetry, and art. If one were to focus heavily on a seminal text, they could point to Virginia Woolf's "On Being Ill," an essay that argues for illness as just as an important focus of literature such as love, relationships, and war. It is interesting that over time what illnesses matter and their effects on characters and relationships in literature have changed. From my current understanding, it seems that disease in literature falls into two categories: you die from it or you can change it. In areas of British and American literature, many would fall ill and die from illnesses like the flu, tuberculosis, and pneumonia. Now, many American writers focus on cancer and mental illness because it is prevalent and relevant to many people. But, it seems that chronic illness, which does not fall in either of those categories, has not been touched on at all in literature.

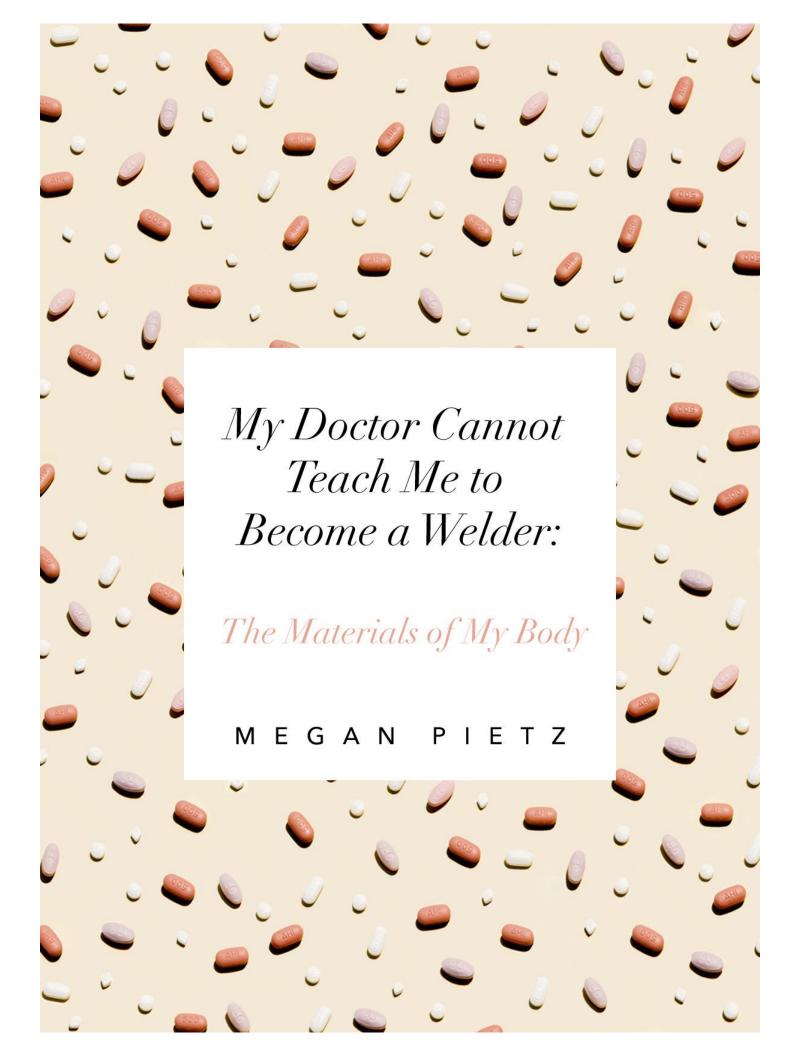
My goal for this project is to assess the presence of chronic illness in modern literature and then create an artifact that represents to the best of my abilities my own

experience, adding to the small number of texts that focus on chronically ill females that are visible to the public. I hope to reflect more deeply and with a better base of knowledge on how my experience has been different from that of my peers and how that has affected my growth as a college student in both an academic and social context. My project will be a collection of newly written work and past work that I have created in relation to my chronic illness since my diagnosis at the age of 10. Because I was diagnosed at such a young age, I have a relatively deep knowledge of my illness but limited in that for much of my life I was given explanation in laymen's terms. By researching my own illness further and combining that with reflection, I hope to better understand how to effectively utilize medical terminology in my personal writing and interactions with physicians. I hope to include a combination of poems from other perspectives, ekphrastic poetry, and the inclusion of personal blog posts from an online blog I have been updating about my experience in order to widen the lens on my experience and challenge myself in my writing abilities.

In combining all of these aspects, the work inside my chapbook would be considered interdisciplinary because I would be bringing in new knowledge from other subject areas and actively integrating information from the medical and scientific community into my creative work. The integration of creative fields with the medical field reflects my ability to connect and weave together knowledge in visible and invisible ways, letting my new knowledge of the medical field insert itself into my creative writing and lens as a writer. The chapbook would have an introduction that briefly explained what my chronic illness is and a general timeline of health events in my life, giving context to the reader and again joining together medical knowledge with the poems

included. By giving readers an understanding of my illness and experience through poems while also providing them with factual medical information, I am providing a well-rounded and informed view point that will allow them to make connections between the medical world and my creative work.

Ultimately, the goal of this project is to have a complete work ready to submit to publication. This means that I would both be ready to add to the body of work regarding chronic illness and that I would be able to have it as an artifact of my own experience. This is especially important to me as I share an identity as both a future teacher and writer, and I hope to use the completed work as an example project in my future classroom during a poetry unit. This would further the interdisciplinary nature of my project and continue to help others learn about and understand the nature of chronic illness.



"The room was the poem, the day I was in. Oh Christ. What writes my poem is the second ring, inner or outer. Poetry is just the performance of it. These little things, whether I write them or not. That's the score. The thing of great value is you. Where you are, glowing and fading, while you live."

— Eileen Myles, *Inferno* 

Thank you to my family my doctors my friends

and to my kind and helpful professors, Francesa Royster and Kathleen Rooney.

Cover art by Asia Shelton (yes, those are my actual pills)

### Am I My Illness Or Is It Just a Part of Me?: Exploring Identity in Writing

As an English student, I have spent much of my time finding both solace and escape through reading, but I have read almost nothing that allows me to connect with another character through illness. I am living with two chronic illnesses that have no known cure: Reynaud's Phenomenon and Scleroderma. Reynaud's Phenomenon is a disease that causes skin discoloration because of poor blood circulation and can cause pain due to numbness and limited movement. When I am cold or under stress, my fingers turn purple; when I am hot, they turn red. Scleroderma is an autoimmune disorder that causes skin to tighten due to an overproduction of collagen and can spread to your internal organs, making it difficult for them to function. Both of these illnesses and their symptoms can only be treated with drug therapy. I was diagnosed at age 10, and as I have aged, I have experienced a variety of other health issues as well as a worsening of symptoms, most strongly with the Reynaud's. However, because neither disease has progressed significantly in the past five years, my rheumatologist assures me that my disease should not progress to the point where my internal organs will be greatly affected.

Though I turn to Eileen Myles, a favorite poet, in the waiting room and subscribe to *New Yorker* as a treat to bring with me to my appointments, I have only found brief contact with illness and the body in my personal reading. Wing Biddlebaum, a character in my selfproclaimed Bible, Winesburg, Ohio, by Sherwood Anderson, moves to town after being pushed out of the school in near Winesburg by the rumor he may have touched a student inappropriately. An older man, he is expressive with his hands, but still hides them away with an air of embarrassment when he notices his behavior. While he was not sick per se, his discomfort and self-consciousness related to his hands attracted me to his story. Flannery O'Connor, one of my favorite authors, suffered from Lupus, a disease similar to my own, but she hid her illness in the traits and actions of her fictional characters and never outwardly wrote about her experience with the disease. As a reader and a patient, I wish that O'Connor had written more explicitly and with confidence about her experience because it would provide insight into her struggle and be comforting to me because of our shared similarities in illness. While I have wanted to hide my hands like Biddlebaum or write my experience through another character like O'Connor, this project is an exercise in confidence as I often feel self-conscious about my illness and outward symptoms, but I understand and want to write about it so that others can see my and other patients' experiences.

As I began to research the role of illness in the literature for this project, I came across an essay by Virginia Woolf titled "On Being Ill." The essay details how she finds it strange that "illness has not taken its place with love and battle and jealously among the prime themes of literature" and that "novels…should be devoted to influenza; epic poems to typhoid; odes to pneumonia; lyrics to toothache." Woolf observes that literature is primarily concerned with the mind because others see the body as "a sheet of plain glass through which the soul looks straight and clear." She believes this is a false statement because our body is constantly intervening as it blunts, sharpens, colors, and discolors our world.

Woolf's point regarding illness as a theme is reality to me as I present my own experiences in the following writings, images, and concluding essay. Often, I have seen illness romanticized, the history of which is detailed in Susan Sontag's *Illness as a Metaphor*, or as a popular plot point in bestseller literature, like *My Sister's* Keeper by Jodi Picoult or *The Fault in Our Stars* by John Green. However, cancer, or any other illness for that matter, often becomes a starting point or basis of a novel about romance or a serendipitous discovery about the meaning of one's life. This takes away from the darker story: the struggle to manage one's body on a daily basis in a complex web of public and private relationships.

Once ill, I did not magically have a boyfriend eager to be my caregiver. I have never seen a book that depicts the conversation one has on a date to apologize for the pills midmeal. A minor tap of the wrong area of my fingertip can make it feel as if someone is stabbing my hand. I have experienced all of the symptoms you hear listed rapid fire at the end of commercials for medication because of the twenty or so pills I take, and most days I will feel nauseous and light headed. In the winter, I wake up with my hands locked tight like a claw, a response to the cold night. My cuticles grow out thick and brown to protect my dilated blood vessels, and every so often sores the size of pebbles peel off the tips of my fingers. Each year, I swallow fake marshmallow fluff mixed with barium to check my internal organs as a part of a swallow test and sit inside a tiny plastic booth and blow on a tube for an hour to test my lungs. These are just two of the battery of tests I undergo at Northwestern Medical Center so that my team of doctors, rheumatologist, pulmonologist, neurologist, allergist, and primary care physician, can make sure that a new malady or symptom is not hiding. The office assistants who take my copays at each visit and my

pharmacist know me on a first name basis. I bring them Christmas cookies in the shape of hands, iced purple, every year.

Much of my life has been spent defining myself as an individual and this is directly related to my being a triplet. My sister, my brother, and I are competitive about many things, a response to wanting to feel separate from a unit, so we have each carved out our places in a variety of subjects and hobbies. However, something that each of my siblings share is that at one time or another, each of us has dealt with medical maladies. Surgery in the fifth grade aided my sister's scoliosis. Recurring ear infections required my brother to have tubes in his ears. My parents knew I had Reynaud's from a young age because of the discoloration in my fingers and intolerance to cold. My dad is a podiatrist and understood that it would be appropriate to wait until I was older to start taking the serious prescription medication my illnesses required. While unexpected in terms of the disease itself, it is common for triplets to have medical issues (thought scientifically it is still unclear why). I was familiar with pain and procedures, as I was born with an exceptionally small mouth that required me to have sixteen tooth extractions. These extractions all happened before fourth grade, when I received braces on Martin Luther King Jr. Day. I always had a sweater with me, made jacket-friendly Halloween costumes, and a particular penchant for snowflake patterned flannel sheets in the winter.

In fifth grade, I started to complain about pain and my almost-middle-school self was self-conscious of my fingers. I visited a rheumatologist at Children's Memorial in Chicago for the first time in spring of 2005. We drove down from Skokie, the northern suburb I am from, and I felt relatively healthy in the waiting room in comparison to kids in wheelchairs or those who wore breathing tubes. I was relatively unfazed by the appointment though the diagnosis of Scleroderma, the more serious illness of the two, was unexpected by my parents. I just wanted to be able to play the drums without my fingers turning colors and have all my friends stop asking me questions about my skin. I did not have any friends growing up with similar issues, but this lack of community did not bother me as I was so focused on staying normal and participating in the team sports, band, dance marathon, and yearbook like everyone else. I provided medical information on forms when necessary, but for the most part did not talk about my illness with friends, teachers, or extended family. I felt I had enough support through my parents and doctors, and frankly became bored discussing details with others because I did not consider my illnesses anything other than a fun fact about me.

Over time, my tolerance towards physical pain and the abnormalities of my body has slowly begun to wear away. I struggle more with the identity of being ill, the stress of a lifestyle that demands balance, and the unanswered question that has hung in the air since I was 10: "Why did I get sick?" While my doctors and the medical literature seem to think it is genetic and my parents think my maternal great grandmother may have passed it down, I have no answer. Often, I joke that it is because my greedy sister stole all the nutrients in the womb. Though I don't believe in God, sometimes I wonder if I became sick as a test of strength and will, to be an example for others of perseverance and a positive attitude. Some days, it feels like a punishment. Other days, it makes my writing feel like a purpose.

I started this project in the hopes of not only contributing more to literature or art that connects to the body and illness, but as a way to provide space for myself to write about something that I have lived with for half of my life. In the following pieces, I have tried my best to include work that allows for universal connection while also working with "the poverty of language" in regards to illness that Woolf so aptly describes. Those who are sick must take his or her pain in one hand and a lump of pure sound in the other "so as to crush them together that a brand new word in the end drops out," as Woolf says. I hope that this chapbook is a product of that action, the physical manifestation of the process of healing I have tried to create on my own, prescriptions of poem pills per se.



#### **Weekend Plans**

#### Age 10:

Mountains of mint ice cream hold pink pill bombs. Methotrexate, an immunosuppressant, sits in eight circle pills. It helps my scleroderma, but I don't know why. My dad sits across the kitchen table as I stare at the bowl in defiance. I do this every Friday night.

Reluctantly, I pick up my spoon and try to distinguish pills from chocolate pieces. They are the size of tic tacs. We hid in them in the ice cream, hoping it would mask the taste. Gagging in anticipation, I raise the utensil to my tongue.

#### Age 16:

The smell of hand soap triggers nausea. I dab my stomach with the washcloth as preparation behind the bathroom door. In the kitchen, dad draws up the syringe – subcutaneous but enough to cause three recurring bruises which have a slight shine under the kitchen light. Methotrexate again, in liquid form. Maybe I'll stop puking every Saturday morning because there aren't pills in my stomach.

I ask him if the bruises will ever go away and he says yes. It is summer and I have a new swimsuit I would like to wear. A green bikini with gold details. The bruises are an unwanted accessory.

#### Age 21:

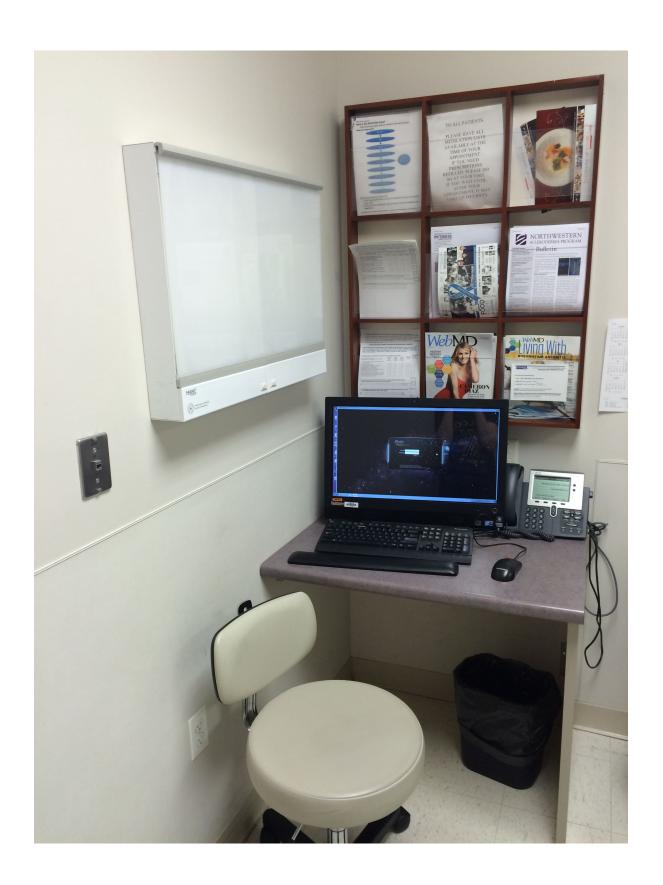
The pink plaid kitchen tablecloth soaks up the sweat of our matching glass bottles – mine ginger ale and dad's beer. My pills are upstairs in my backpack, all jumbled together in a green Ziploc bag . Yellows and pinks. Capsules and tablets. Dad would be mad if he saw – interactions, he would say. I don't care because I'm in charge now. It's my body, so I'll deal with the consequences.

Sipping simultaneously, we watch the moon between our trees through the kitchen window. A new Friday night, unmarred by medicine.



### My inhaler, my boyfriend

After weeks of bad weather, we took a stroll through the fall leaves of the park. Cider packed, we wandered hand in hand, commenting on colors and the smell of the change of seasons: wood smoke and a hint of mold in the yard scraps on the sidewalk. As we started up the hill to our spot under the perfect orange tree, I began to feel ill. Bent at the waist, I lean my hands on my knees. "Al?" I said. "Albuterol?" I pressed my mouth to his red, plastic rectangle. There's nothing more romantic than taking him as needed.



#### My Best Friend, Eileen Myles

Eileen,
I met you
accidentally
on a website
last summer.
Read you on
the stairs like
I was drinking
a glass of water.

I loved you so much that I asked you to lunch and you showed up at my backdoor. We have sleepovers now. Even though I never liked them as a kid. I preferred my own bed and I hated playing with Bratz dolls.

Eileen,
thank you for
sitting in
waiting rooms
with me.
I think you
like to observe
all the walkers with
tennis ball bottoms.
You find the
stapler clicks
and printer yelps
a perfect white noise
for writing poetry.

Eileen, you know when I'm nervous. You always pull out "Not Me," ask if I'd like to hear a poem. I nod. Reciting "Peanut Butter" without issue or care, you make the hospital feel like a gallery. Instead of being sick, I'm the audience, waiting for more.

Eileen,
Ei-Leen,
I-Lean.
"I lean on your poems,"
I say.
"You know that, Eileen?"



# Dreaming of my Mother's Flowers at a January Appointment

The soft edges of cotton candy colors rest gently on fresh stems. A bouquet ready for presentation, as if the dew on the petals is still there.

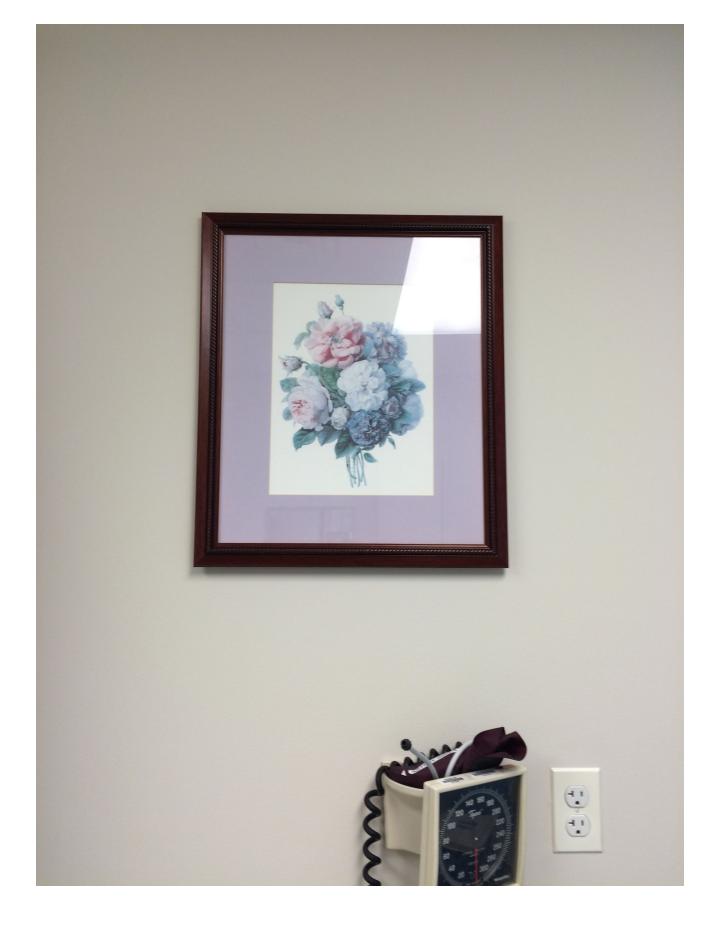
Under the fluorescent lights, I wonder where the painter got them from because peonies like that can't just be conjured up from the mind. We are in Chicago and outside the slush is gray and cold. I am alone and my parents are at work. This image is summer in my backyard in Skokie, preferred.

I know that peonies produce nectar so ants are attracted to them. It encourages the ants to help open up their double buds. I shake them off my parents' peonies when cutting a bunch for our table. The plants engulf our side fence on

the south side of the house, leaning on one another for support.

We have peonies because my mom took some of my grandma's plants.
They were in Western Springs, another suburb but with more money.
They were on the side of her house too, a contrast to the brick. A green inheritance of sorts, the roots of one planted at the house of another.

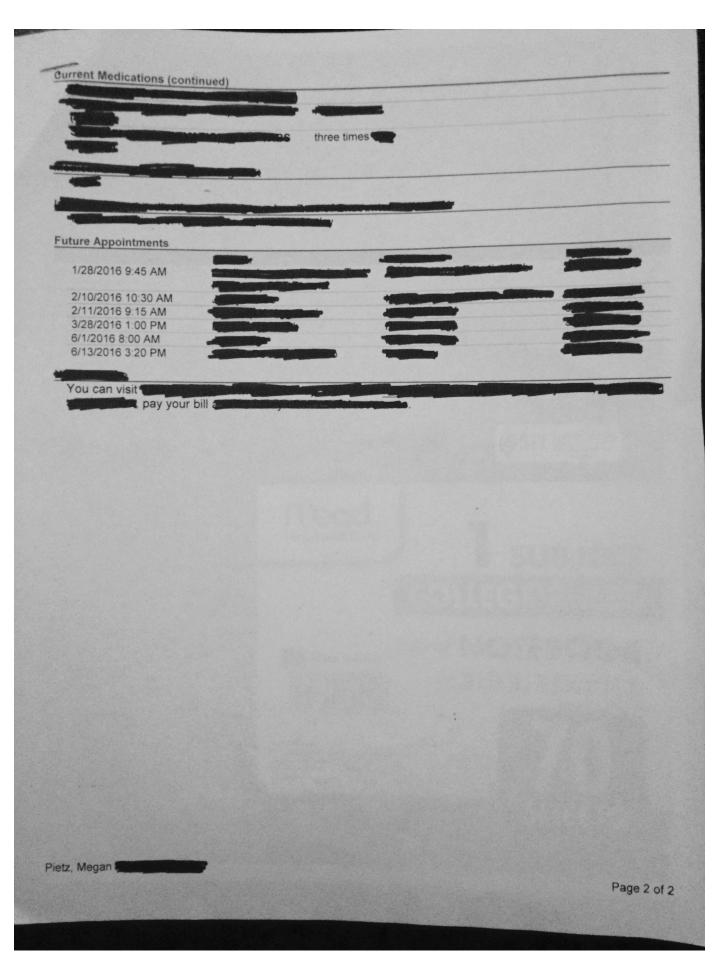
I wonder if I'll take some peonies too.
I want a house with a yard and a side garden.
Someone to help me take care of them.
That's an image deserving of a frame.



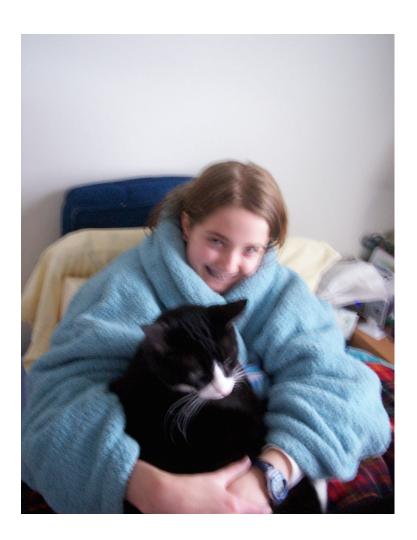
The following pages hold a black out poem. A black out poem is where the writer erases existing words on a page so that the uncovered words create a poem. For this poem, I used an after visit summary from a past rheumatology appointment at Northwestern. Medical files are supposed to be kept private, mostly for legal reasons and some for personal. Anyone who is ill has mounds of paper that detail their body and their personal information, and these are considered extremely sensitive.

These summaries tell a patient all their basic information, their diagnosis, an updated list of medications, a list of future appointments, and instructions on how to pay your bill. In short, this is not a document you would leave around for someone to pick up and read. Instead of hiding these details, I have chosen to highlight specifics to speak to the feelings of embarrassment that can crop up due to the shame of being less than normal while ill.

M Northwestern Medicine® Description: 21 year old female Pietz, Megan 1/27/2016 8:00 AM Office Visit Please take a few moments to review this summary of your visit. We recommend that you keep this information private as it contains your personal health information and instructions. Vitals BMI BP Pulse Resp 20.51 131 lb (59.421 kg) 5' 7" (1.702 m) 16 115/75 mmHg kg/m2 TABLET 3 TIMES DAILY (Taking) (Taking) DAILY DAILY DAILY A MEAL Pietz, Megan Page 1 of 2



Here I am after my first Scleroderma Walkathon in Wilmette, Illinois in June 2005. This is in my bedroom at my parents' house in Skokie. Oprah donated all of these blue chenille robes, and the volunteers knew I could have one because they saw my purple fingers. It was an unusually cool June day when we got home, so I bundled up in the robe and tried to force our cat, Boots, to sit with me. He was a relatively new addition to the family. We adopted him when my sister, Lindsay, had spinal fusion surgery because a patient of my dad's brought him to the office and asked if my dad wanted him. We did not have pets, but it was about the time my parents had planned to get one. Plus, Lindsay and my mom were home as Lindsay healed from surgery, so Boots could have help adjusting and be supervised while they were around. The robe is in my apartment in Chicago now, and I still wear it all the time.



Me, as Marie Antoinette, my sister, Lindsay, as a mad scientist, and Alexa, one of our childhood best friends, as a goth princess. This was taken the day after the 7th grade Halloween dance, right before we went trick or treating in Skokie, the self-proclaimed largest village in the world where I'm from. As always, Halloween was cold and wet, so I needed my jacket. I was mad because my costume was "ruined" because of it. My pieces of foam that made the skirt look large and regal looked odd smashed by the jacket.



The first winter of my diagnosis, my mom thought it would be a nice idea to bring in some treats for my monthly appointment around Christmas time. I was almost 11 and it was the end of 2005. Instead of regular holiday cookies, however, she thought it might be clever to make them hand cookies that looked like they had Reynaud's. I agreed, laughing. We took a trip to Michael's for a hand cookie cutter and some purple sugar sprinkles, and we used our typical sugar cookie and icing recipe.

When we brought them to the office at Children's Memorial in Chicago, my rheumatologist, Dr. Klein-Gittelman, laughed and immediately went out to show the other nurses. They all thanked my mom and me on the way out of the office. I was glad they liked them and approved of our sense of humor.



I found this note on a blood pressure cuff at the NorthShore Allergy Clinic in Lincolnwood, Illinois. When I was in high school, I ran cross country for two years. In that time span, my sister and I both somehow developed severe outdoor allergies and exacerbated our exercise-induced asthma. We began to receive allergy shots, which can take years to finish.

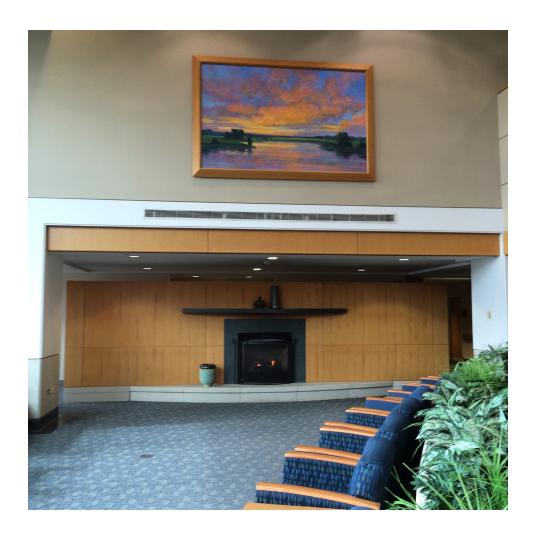
I took this picture in the fall of 2015 when I was 20. A cold had triggered my asthma, and I needed to be checked to see if I should be taking more medications. This was one of the first appointments of a month-long deluge, resulting in the cancellation of my first trip to Europe in December 2015.



This is the lobby of Glenbrook Hospital in Glenbrook, Illinois. It is the hospital where I was originally diagnosed with Scleroderma and Reynaud's because they have a branch of Lurie's (formerly Children's Memorial) Hospital here.

When I got sick in the fall of 2015 at the age of 20, I messed up the routine of my allergy shots. With the progress I made, I should have been getting them every six weeks. However, with all of my breathing problems, I had to skip almost two months of shots. This meant I was back to getting shots once a week to build up my tolerance to the allergens they injected in me.

Normally, I would go to the NorthShore Allergy Clinic in Lincolnwood as it is closer to my parents' house in Skokie, but it was difficult to get there by public transit during the regular school year and they were only open for allergy shots when I was in class. I had to start going back to Skokie, where my parents live, and driving to Glenbrook every Saturday to receive my shots.



This is me and Eileen Myles when I met her on Halloween of 2015 at Women and Children First Bookstore in Andersonville, a neighborhood on the north side of Chicago. She was promoting the re-release of *Chelsea Girls* and a book of new and old poems called *I Must Be Living Twice*.

Before the reading, Eileen came in and sat across the aisle from me. I immediately started sweating and turned bright red. I fumbled with my copy of *Not Me* and the newly purchased *I Must Be Living Twice*. After one woman asked to have her books signed, the older lady next to me pushed me to get mine signed too. I told Eileen I liked her socks and she said she tried her best to match her sweater.

Though I got misty-eyed during the reading, I pulled myself together to get a picture afterwards. I was sort of embarrassed to ask for a picture, but I figured it was ok because I had already gotten two books signed.



This is one of the rheumatology treatment rooms at Northwestern Memorial Hospital in Chicago. All of the rooms have the same color scheme in terms of the chairs and curtains, but the art can vary. I liked the art in this room because I thought the colors matched the color of my fingers well.

As you can see from the perspective of the picture, I'm not in the treatment chair. I like to sit in the chair next to the doctor's computer when I get in the room because it makes me feel like my mom. I always picture her sitting cross-legged in a chair next to the doctor as I look at her from the treatment chair, so maybe I'm pretending someone else is getting treated besides me when I sit there?

The fluorescent lighting and antiseptic smell don't tend to make me angry or nauseous anymore. It is mostly a resigned anxiety. To combat this, I started taking images of treatment rooms as a way to focus on a new perspective rather than impending information.



This is one of several images I have of just my hands and toes. I don't take these as often as I should now to document the progression of Reynaud's, but I used to take them all the time. I am better at describing the progress of my illnesses to my doctors now and the coloring has not changed as drastically as it was right after I was diagnosed in 2005. Here, I am holding my hand over the dining room table at my parents' house in Skokie. I think this is about when I started to see what I call tie dye hands, red and purple together as opposed to a singular color.



This is a toe calcification, which means there is a mineral buildup under my skin that can be painful and is a result of my Reynaud's. While not the most high quality picture, the craggy edges of the sore give me a clue that it is calcium and not a callus. A callus is a build up of skin due to rubbing or pressure and lots of people have them, but the calcification is more serious because it means there is a breakdown of skin and circulation related to my Reynaud's. These also occur on most of the knuckles of my fingers.



I am holding up my fingers under the light of my nightstand lamp in my room at my parents' house in Skokie, Illinois here to show my doctor the sore forming on my middle finger. My middle fingers are the most affected on both hands, and I'm not sure why. I took this image mostly because I was concerned it would become an open sore, which means my body is more susceptible to infection. Luckily, my sores peel off relatively often and do not leave wounds. It is unlikely that I will ever have open sores because my illnesses are not that progressive, but it is a definite fear of mine.



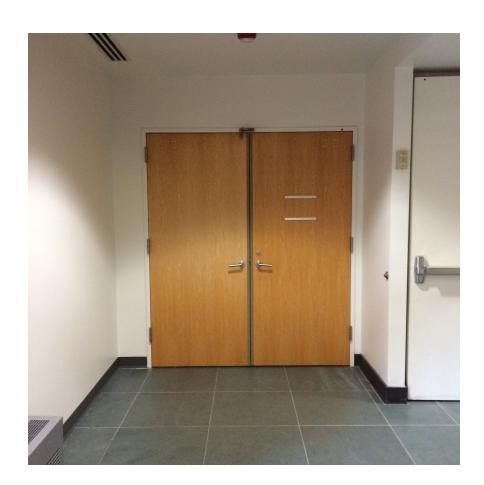
This is a treatment room at the Northwestern Immediate Care center in the Lakeview neighborhood of Chicago in the winter of 2015. I took this while waiting for the nurse to come in, as I was trying to distract myself from a headache and subsequent nausea. This was happening at least three times a week. While this appointment did not help my headaches, it did help me get a referral for a neurologist, yet another doctor to see. The neurologist subsequently told me I had both migraines and cluster headaches.

I was expecting my winter break to be relaxing and restorative as I have gratuitous six-week winter break because I attend DePaul. Instead, I spent my time going to appointments and sleeping, with some Gilmore Girls in-between. The treatment room art became a game. Did it match the chair? What was its theme? I liked this chair because I thought it matched my purple fingers.



Behind these doors in May of 2005, I was officially diagnosed with Scleroderma and Reynaud's. This was in the Children's Memorial, now named Lurie, hospital wing at NorthShore Hospital in Glenbrook, Illinois. It was a chilly spring day, and I remember my doctor inspecting my special down mittens from LL Bean. She approved, and the proceeded to hand me a sheet called "Winter Tips" as if it would be a Bible for the rest of my life. As she said, "Winter will be the worst time for you, always."

I read the sheet, kicking my feet against the hollow khaki-colored metal of the exam table, as my mom called my dad to give him the news. It echoed against the truck-printed wall splash. It smelled like pink doctor soap and new paper towels. The treatment room had a heat lamp I kept switching on to stay warm. I wish I could remember in more detail what my mother and looked and sounded like on the phone. I wonder if my brain purposely trashed that memory because it didn't want me to have it. Either way, the thirty minute car ride from Glenbrook to Skokie, my home, took too long.



This is a mold of my mouth taken in the late winter of 2016. My dentist is in the professional building at Old Orchard Mall, now called Westfield Shopping Center, in Skokie, Illinois. I was experiencing a lot of tension headaches and jaw pain, so I scheduled an appointment thinking that it was maybe my wisdom teeth causing an issue. But I was wrong. Apparently, I was unconsciously clenching my jaw throughout the day due to stress. This made sense to the dentist after we had a brief chat about school, work, and life.

Whenever I go to the dentist, I always get distracted by the pictures of him and his family skiing in Colorado. They all have gray jackets and white teeth. They look too happy, almost like an advertisement. I wonder if each of them has something wrong with them.

I looked at the pictures when they took molds of my mouth. Even when they used the kidsized trays for the goop, they still split my lips on both sides. When they took the trays out, my teeth felt cleaner, like they had been dusted. A few weeks later, when I came to pick up the mouth guard and retainer combination (I needed one for my old braces), they also gave me the mold of my mouth. It's supposed to be able to be used again in case I break my retainer, but a few of my smaller teeth broke off. It sits on my desk now, a weird tchotchke.



This is the Pietz farmhouse in Saxonburg, Pennsylvania. This was taken Thanksgiving of 2015 on a disposable camera. I took the picture looking down at the house on the way to a walk up the hill, a better vantage point.

My two favorite parts of this house are the oxidized copper roof and the side porch held up by four massive wooden Georgian porch columns painted white. It dates the house, but according to my grandma, they were odd details to have on a farmhouse when it was built. I have spent time here in all the seasons, but I am mostly here for the holidays (Thanksgiving and Christmas) and briefly in the summer.

My grandma no longer lives here because she is too far from the rest of my family. The stairs are steep and slippery, and something could easily happen when no one is around. Inside, the house has become a shell of itself. The furniture is not what I remember from when I was a kid. The scratchy mustard couch in the living room has been replaced by an old leather couch owned by an uncle. There are toys besides the custom built barn that holds the tractors and the Barbie ice cream shop set. The kitchen cabinets hold plastic cups instead of my grandpa's mugs covered in veterinarian jokes.

Even though we don't stay in this house when we visit anymore, I love spending a day at the farm. I check out my grandpa's old books, say hello to the horses in the pasture, and listen to the red winged blackbirds that hide in the overgrown cattails surrounding the pond.



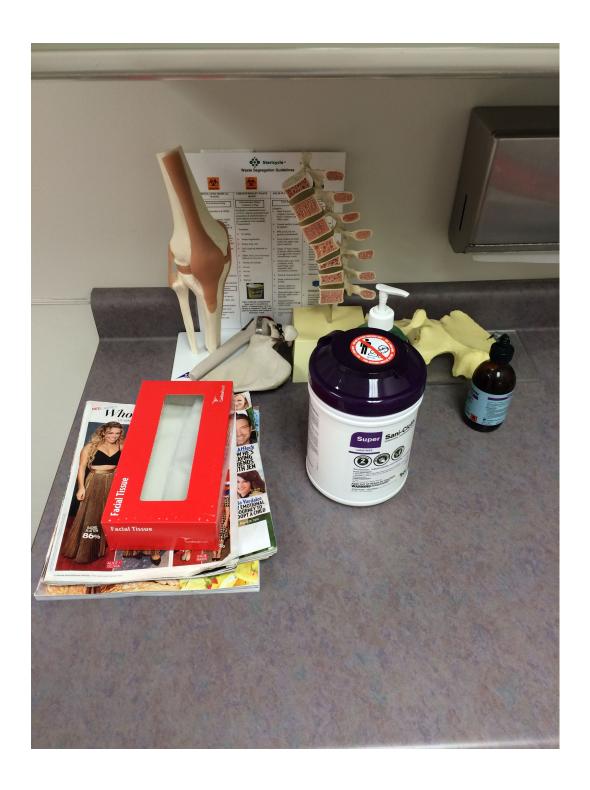
#### **Materials of My Body**

I'd like to think that my mental self is more plastic than my body but the truth is that they're both made of metal.

The comfort and intimacy of touch, removed from my hands without my consent.
Bony, small, and sweaty, my hands are not an ideal puzzle piece.
I am unable to make a whole with someone else.

I did not understand that my illnesses are forever until I was embarrassed to hold hands with the boy I liked.

I wanted to bend my fingers so that they fit into the crooks his hands, but my somehow my doctors cannot teach me to become a welder.



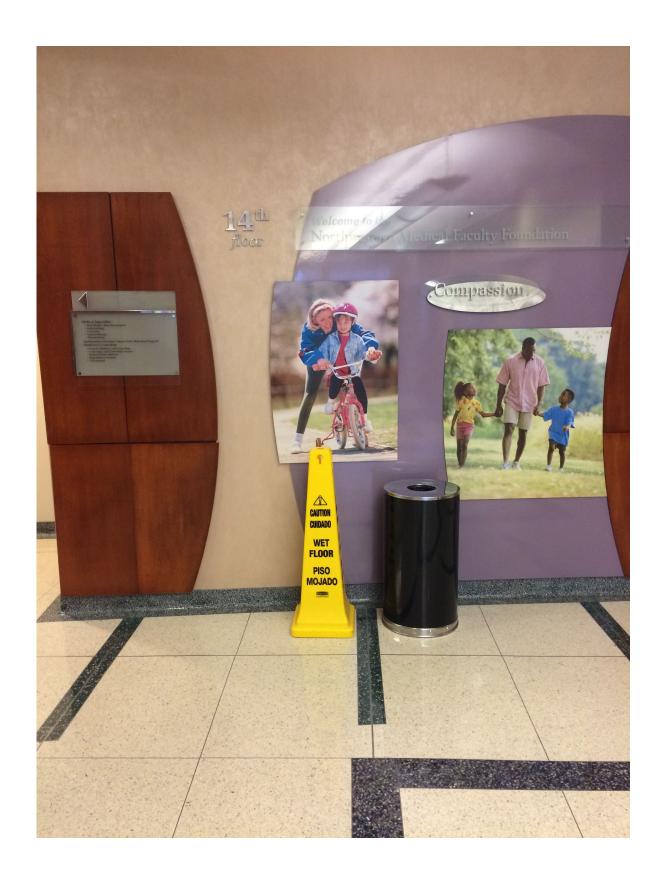
#### The Commute

The bus has body language today.
The prescriptions in my hand read: Microgestin<sup>1</sup>
Revatio<sup>2</sup>
Gabapentin.<sup>3</sup>

The bus turns the corner in a mood. I spill my tea on the papers.

Incoherent syllables to some, my medicines read like a personal dialect. I wonder if the man next to me is reading over my shoulder, the tiny scribbles of doctor handwriting, confused.

- <sup>1</sup> Microgestin Fe 1/20 is used for prevention of pregnancy. It may also be used to regulate the menstrual cycle. Microgestin Fe 1/20 is a combination of 2 female sex hormones, estrogen and progestin. You should make sure to take this at about the same time every day otherwise you may increase your risk of pregnancy. You cannot get pregnant because you are a student but more importantly a sick person and you cannot risk passing your shitty genes onto someone else.
- <sup>1</sup> Revatio (sildenafil) relaxes muscles found in the walls of blood vessels and increases blood flow to particular areas of the body. Grapefruit and grapefruit juice may interact with sildenafil and lead to unwanted side effects. Avoid the use of grapefruit products while taking Revatio. You will want to buy grapefruit body wash but you will hesitate because you do not need a red rash on top of your purple fingers. You will never get to try the grapefruit La Croix either. This is a problem because you are a sparkling water expert.
- <sup>1</sup> Gabapentin is an anti-epileptic medication, also called an anticonvulsant. It may also be used for other conditions as determined by your doctor. Some people have thoughts about suicide while taking this medicine. Your doctor will need to check your progress at regular visits while you are using gabapentin. You will say you are fine even though you aren't because who is actually happy anyways? You are fine. Stop complaining. Talk to your therapist once a week and buy a chocolate frosted doughnut afterwards.



# I Know I Won't Die Young Because Doctors Say Nothing Will Progress. But My Anxiety Says Otherwise, So This Incomplete List as a Quasi-Will is Just Existing to Calm My Mind

Please follow these requests to the best of your abilities, Mom, Dad, Lindsay, Matt, whoever reads this. But don't skimp on the food. That's the best part.

#### Location:

Outdoors and not at a church. I am not in heaven because here on earth my body was a model for purgatory.

Play Hummingbird by Wilco.
Only when everyone is silent,
not as some background music.
The Band can be background music
if you really needed a suggestion.
Shouldn't you know me better?

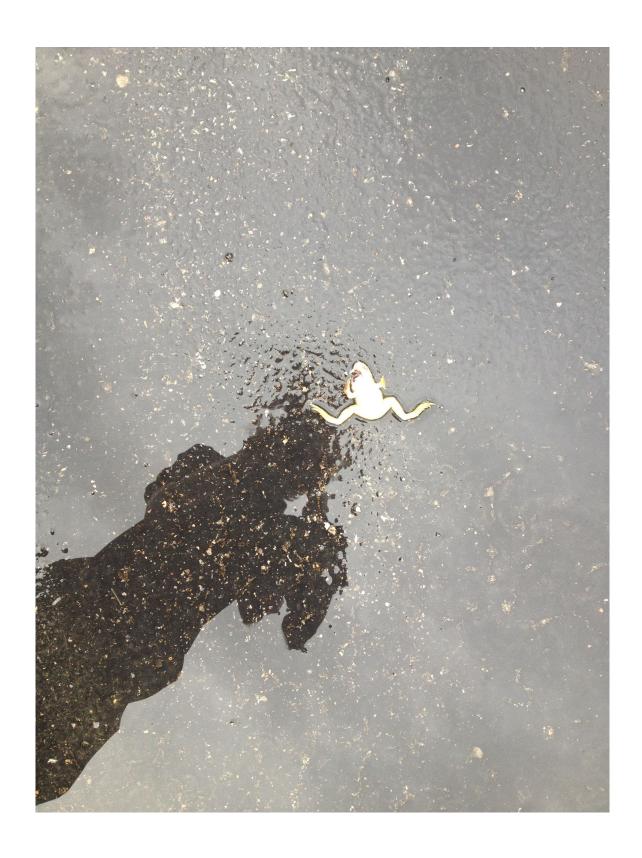
After my eulogy, read "Peanut Butter" by Eileen Myles. Ginger ale should be toasted immediately following. Glass bottles only. The tinkle is just so satisfying.

Then, eat.
Bruschetta spread on tables with Twizzlers in glass jars.
Lots of hot cheese.
Mom's mint brownies too.

Lilacs and sunflowers preferred. Daisies equally wonderful. Maybe some ornamental grass and peonies too, now that I'm thinking about it.

My personal library should be set up like the stacks: outside used bookstores. Winesburg, Ohio, Song of Solomon, The Argonauts.
Old metal carts or worn wood.

No real sense of organization. Everyone should take one, a party favor.



## On the Day I Received Twelve Botox Shots in Each Hand as an Experimental Treatment, I Thought About Tiny Megan on a Saxonburg Summer Evening

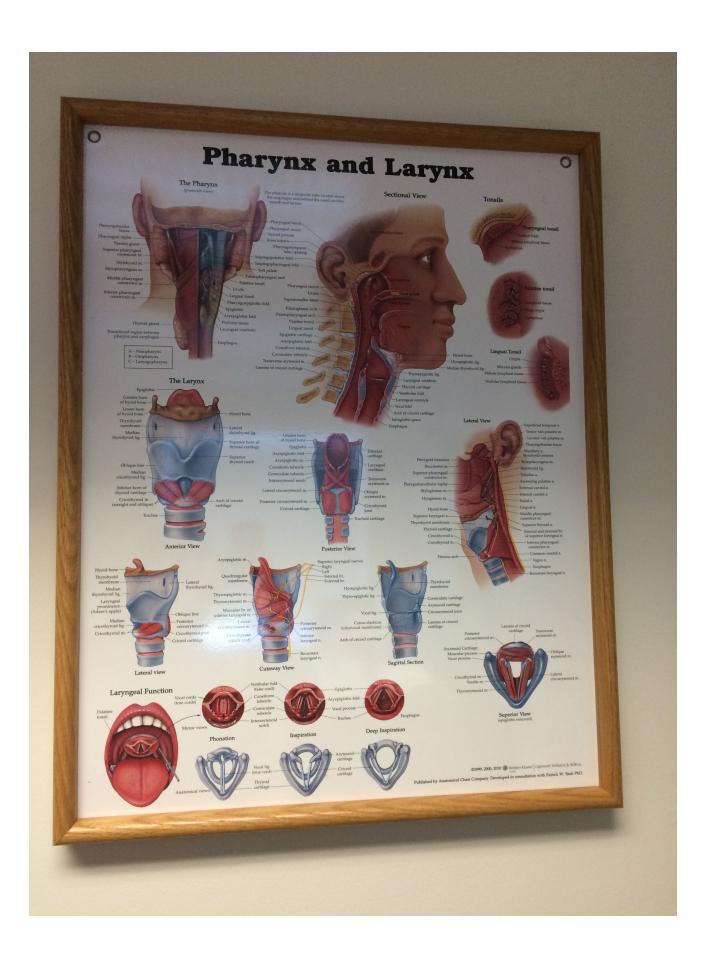
The copper-tinged chimney erupts with bats at dusk. We wait for them with reverence, straining our necks as we poke imperfect holes in the lids of Dad's old Kirkland peanut jars. Fireflies are the next best thing.

The river stone ledge acts as a prop for our limbs, keeping us safe from the looming pines that hold the bats and their friends who we speak about as people. Our excitement like a belly full of fading pop rocks.

Now dark, the bats have waved goodbye. The jars of fireflies are left empty at the door so we can catch our friends at the same time tomorrow. The screen door stays open as we wipe our muddy feet on the Labrador Retriever door mat.

Inside the house, wrinkled wooden steps lead up to the cool relief of the shared bathroom tile. Who would spit first in the sink? A race between siblings, of course.

In bed,
my sister and I tug at
the ends of the
blue and white diamond quilt.
We sleep in the shape of
antennae – two J's, one backwards.
Through the screened windows,
fingers of wind push hair
behind our ears.
We are ready for sleep.



#### The Art of Illness: Writing About the Self as a Reflective Practice

In Susan Sontag's *Illness as a Metaphor*, she discusses that much of the public up until the early 1900s saw sickness as a way to make people interesting, more singular. Those who were sick could essentially remove themselves from everyday life on an endless search for a healthy place, allowing them to be both motivated and controlled by their illness. When I started writing more about my diagnosis, I wondered how that writing would affect my relationships and me. I was hesitant about starting this project because I thought I would be trying to put myself above people and say, "Look, my life is harder than yours," possibly alienating myself. I worried about sounding whiny to others, that I would not be doing productive writing in the sense it would be selfish in subject and in purpose. Are my rare illnesses better than other illnesses? Was I trying to make myself more interesting others? Was I figuratively pimping out my illness to draw people into my writing? I debated whether or not it was worthwhile to make anything public and maybe writing about illness was more of a personal, reflective exercise rather than for an audience. I was starting a project to write about illness, a difficult and more serious topic to some, in a genre, poetry, that people find confusing and academic. It felt elitist and intimidating. Most of all, I wondered who would, in the end, care about my experiences and me thus far.

As I write this essay, my fingers are dark purple. I am not speaking to anyone directly about my fears because the reader is only looking at this page, but this physical response means so much to me. My fingers tell me I am nervous, like when I speak in front of a large group or meet someone new. So I think, "Why while writing?" After writing all of these poems, reading further about illness in literature, and living my life as usual, I should feel proud and satisfied about the work I have done. I think I am nervous because this chapbook feels to me as if I am letting my illness cement itself in my identity. I am scared to be sick for the rest of my life. I am scared that all of these medications are doing terrible things to my body that I won't know until years to come. I am scared that I will not be able to meet all of my goals for myself and that it will hinder any kind of relationship for the rest of my life. At the same time, I feel relief that I can talk openly about my experience and that I can share it in a tangible way with others.

Reaching the end of this project has made me ask myself if I liked what I found while self-researching. When I think of research, I think of looking for something specific. There is an active journey and the hope for an end. There are questions that I am trying to answer,

like "Why am I sick?" and "What does being sick mean?," and I am looking for the sources that answer those questions and inform them. When I reflect, I may be focusing on a particular topic, but I may not have a specified result. What matters more is the idea of catharsis. As well, this idea of research is different from reflection for me because I tried to look at my experiences from different lenses, like those of my parents and my younger self, in the poems I have included in this chapbook. What did my parents feel? How has it affected my love life? Is my college experience that different from anyone else's because I am sick? These were tough questions to answer, especially because I was not quite sure I wanted to not only know, but also fully grasp, the answers to some of them. In a sense, the self-research made me take a look at all the moments that I felt defined my illness and see them differently than what I had imagined being on a page.

"On the Day I Received Twelve Botox Shots in Each Hand as an Experimental Treatment, I Thought About Tiny Megan on a Saxonburg Summer Evening" was going to be a poem about what it feels like to give your body over to an experimental, potentially useless treatment, but instead became a moment of reflection about myself as healthy and naïve. I wrote "I Know I Won't Die Young Because Doctors Say Nothing Will Progress. But My Anxiety Says Otherwise, so This Incomplete List as a Quasi-Will is Just Existing to Calm My Mind" at my parents' house in the suburbs when I wanted to write about the incalculable pain of a migraine. However, it became a poem about my trait of being a control freak and wanting to find ways to control my own death and make it easier, in a possibly humorous way, for the people I love.

Much of my understanding of my illness came together in roundabout ways, as exemplified above, so I do not think, nor do I feel comfortable saying, that I came to any conclusive answers regarding the questions I posed earlier. However, I do think what I have come to understand is that my diagnosis is not a removable aspect of my identity. I like to be a student, a sister, a teacher, but all of those identities are changed or affected in some way by my illness. I cannot be the friend I want to be at times because I do not have the energy. It was difficult to complete this project at times even with the help of voice recognition software because my hands and vocal cord dysfunction, a slightly new health problem that causes my throat muscles to tighten, were flaring up. When I visit my parents in Skokie, it is usually out of a need to rely on them as opposed to alleviate stress in all of us. These realties continue to be difficult for me, and the writing of this project has only made my illnesses come into sharper focus in my life.

At times in this project, I felt a mixture of both resignation towards my illness and a revitalized attitude to find ways to improve my health. Sontag notes that many people who are sick believe they have an active role in healing themselves and there is some way they can control the uncontrollable in their bodies with a different attitude. Or, they must take on the role of a fighter in this battle against something invisible with a vocabulary of war. I have consciously accepted that my diagnosis does not have a known cure. I personally reject the battle language of illness that many find empowering because I find it hollow and false. Much of my health is at the mercy of drug companies, government funding, and private insurance. While I try to follow a healthy lifestyle and think positively, there is only so much I can do.

However, the process of writing, revising, and collaborating on this chapbook has showed me that I am not a warrior against my illness but a tamer of it instead. My mind is just as important in accepting illness into my identity, and I find it more empowering to make art that looks at illness than to talk in platitudes with others. So much of me exists on paper already in the form of medical files, notes from doctors, and prescriptions. I exist as a whole person on paper just as much as I do in the flesh, and when I read my poems, I am happy I am contributing to that paper person in a way that I have control over. This is especially evident in my erasure poem of my medical file, where I literally am in control of the words on the page that I did not write about my own body. I was able to choose the words I wanted to stick out and to feel pleasure in the blacking out of words I did not like. This feeling allows me to push aside how physically and mentally taxing it would be to actually try to fight what I cannot see inside me. Even just writing about my experiences and having to relive certain difficult moments was trying. In terms of being realistic, I do not even think I could be a warrior against my illnesses because, as there is no cure, the resources to win the battle are unclear.

However, even in my paper self I have created, I have set many personal limits regarding what I share about my illness with others. I feel privileged to have control over how my illness, in some ways, presents itself in a public space, as my symptoms are not always immediately visible. This wavering of private and personal is what I also tried to touch on and play with in the inclusion of personal photos. Spaces like a treatment room, which may seem out of place on the page, gives the familiar a sense of unfamiliarity. The zoomed-in shots of skin look both intriguing and grotesque. One wants to look away, possibly too much of a glimpse of the private they have imagined and not experienced, but

for some reason they are still interested. However, I think that the images themselves acting as breathing spaces between the poems and the poems themselves balance this possible discomfort by indulging in the romantic aspect Sontag describes in her book, an example of this being "Materials of My Body." The balance I made still allows me to believe I have painted an honest portrait of my own experience and mine only. This honesty, in part, comes from feeling comfortable about the in-between of poems and prose, personal essay and reflective essay, and non-fiction and poetry. I did not feel as if one genre of writing or a specific set of genre rules was appropriate for my illness, especially because I did not think it was fair to put my own experience and my reflection or that of others in a box. The use of various forms and sets of rules made me able to write in a variety of ways about my illness, while making it a more engaging collection for the audience as well.

I find hybridity engaging and liberating, and while some may disagree about the rule breaking and bending, this skepticism matters less to me because it allows me to convey my experiences to an audience that I feel is honest and continues to interest readers. While my introduction essay quotes Woolf's call for literature to include more about illness and I agree with her, by no means did I expect two essays and a handful of other writings and photos to encompass my experience or help others see and feel it. However, I think that this chapbook has started a new path in my understanding of myself, my illness, and the relationship between them. Similar to the style of the epigraph, there is meandering to do before the pay off that comes with the last line. I am excited to see where it takes me, illness and all. I hope that when this comes into the hands of others, it not only teaches readers about me, but also offers a new perspective on what it means to think of the many facets of the self and the way they all mix in complicated ways.



#### **Works Referenced**

"On Being Ill" by Virginia Woolf in *On Being Ill: with Notes from Sick Rooms* by Julia Stephens *Illness as a Metaphor and Aids and Its Metaphors* by Susan Sontag

#### **Works That Influenced This Project**

*Not Me* by Eileen Myles

*Ariel* by Sylvia Plath

*Edgar Allen Poe & The Juke-Box: Uncollected Poems, Drafts and Fragments* by Elizabeth Bishop

# Other Authors I Enjoy Who Write about Illness and the Body

The Cancer Journals by Audre Lorde and miscellaneous poems

Migraine by Oliver Sacks

Blue Nights by Joan Didion

Deenie by Judy Bloom

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In lieu of a more traditional reflection paper, I have written it in an author Q&A format.

Q: Before we get started with the interview, can you give us a bit of background on your illnesses?

To make things more efficient, I'll read you the open paragraph from the first essay in my collection:

I am living with two chronic illnesses that have no known cure: Reynaud's Phenomenon and Scleroderma. Reynaud's Phenomenon is a disease that causes skin discoloration because of poor blood circulation and can cause pain due to numbness and limited movement. When I am cold or under stress, my fingers turn purple; when I am hot, they turn red. Scleroderma is an autoimmune disorder that causes skin to tighten due to an overproduction of collagen and can spread to your internal organs, making it difficult for them to function. Both of these illnesses and their symptoms can only be treated with drug therapy. I was diagnosed at age 10, and as I have aged, I have experienced a variety of other health issues as well as a worsening of symptoms, most strongly with the Reynaud's. However, because neither disease has progressed significantly in the past five years, my rheumatologist assures me that my disease should not progress to the point where my internal organs will be greatly affected.

Q: When did you start writing the content that makes up the book?

I would say I started writing creatively near the end of high school. Since then, a lot of what I've written has been about three topics: my health, boys, and my

family's farm in western Pennsylvania. However, my health started becoming a regular writing topic for me in August or September of 2015 because a whole smorgasbord of issues popped up, mostly related to my breathing and Reynaud's. Any time I felt a need to write in that period, it was because of an issue I was having with medication, something I was feeling that I would try and write about to understand it better, or because I was in so much pain that I wanted to make it useful. In terms of the poems that are actually in the book, some of those were drafted in bits and pieces starting in the summer of 2015 because of a call for writing related to illness that I submitted to, but they have changed drastically since then. I read the original poems the other day and said "Whoa" out loud because the original versions are so flat. The two essays in the book were partially inspired by an essay I wrote to post on a personal blog for World Scleroderma Day in June of 2015. Similarly, that essay was inspired by an essay I wrote to apply to Boston College my senior year of high school, which would have been written sometime between October 2012 and February 2013.

The three topics that I mostly write about (health, boys, and the farm) are interrelated for me though, which is why all of them are included in the collection. That is something I am particularly proud of in regards to this project. When I explained this project to people, many asked, "It'll just be about medicine and pain and things then, right?" While that is partially true, writing about illness is complex because, at least in my experience, it affects every aspect of your life. My whole life is not pills and pain and appointments, though it can feel like that. It was important to have a collection that tried to touch on more than just "look at all these crazy

medications I take!" or questioning why I was sick and such. In one of my essays, I talk about how I was worried about illness was an uncomfortable and sometimes intimidating topic. Plus, I was writing poetry, which many also feel requires a special set of skills or an invitation to some sort of secret club to "get it." I still wrote poems because that's what I write all the time. Then, I added the essays to give the readers some more background information about myself and my illnesses. In the revision process, I added a photo essay. With all of these forms, I felt especially confident that anyone who picks up this collection will gain an insight or learn something new, big or small, about the experience of illness in general or about my two diseases.

#### Q: What was the hardest part to write?

The hardest part to write was definitely the captions for the photo essay. Those split the grouping of poems in half. It was the last piece I added to the project, and an idea posed to me by one of the professors helping me with the project. She wanted me to expand on the captions that I had included with the photos I had been using to create some breathing room between poems, but the captions were becoming detailed. It then made more sense to just totally expand the captions into paragraphs, or more, and give them a separate space in the book. A lot of the difficulty that came with writing the captions was not censoring the details. Self-censoring was something I struggled with writing the entire project, mostly because the details feel mundane and repeated for me and it makes they seem unimportant. With these captions, I laid it all out on the table in terms of the details so that the reader could decide what was interesting for themselves. It felt very stream of

consciousness to write them. In fact, when I sent them to a friend for a feedback, I sent them the first drafts just to see the response. And for the most part, they thought they were interesting and making sense, so while they were the hardest to write in terms of including all the details but the least revised pieces. I think that's because so much of it was just giving an unfiltered history of the photos and a bit of reflecting on the photos themselves. Ultimately, I'm super pleased with the section and it's something that I look forward to expanding upon in the future.

### Q: Who took all the photos and when are they from?

I took all of the photos aside from four. The photo of me and my cat was taken by my sister. The Halloween photo was taken by my mom and so was the hand cookie photo. A woman in line to get Eileen Myles to get her to sign her books to took the photo of me and Eileen. Everything else was taken in the past year. When I had a bit of a flare up in terms of being sick in September of 2015, I started taking more pictures of hospitals, treatment rooms, and such because it was something to do while I waited. It was also a response to social media culture. So many people post a picture or two a day of what they're doing on an account, but it's always stylized and cool. At least the people I follow. Most peoples' responses to a good Instagram seems to be "Oh, I wish that was me." I tried to push against that a bit and make fun of it. I took a lot of mirror selfies in treatment rooms with captions like "Fall's Hottest Accessory: Nose Clips for a PFT," which is a breathing test where you blow into a tube different ways for a bunch of times with and without clips. I looked ridiculous, but I was posting my everyday life. However, I didn't post a lot of the

photos that didn't include me because I had planned to write more on a Tumblr titled "Diary of a Sick Girl" and include those with the posts there. It didn't really come to fruition, so I thought the photos could come to use in this project. Originally, I had an idea to write a collection that consisted only of ekphrastic poems in response to waiting room and treatment room art. Another friend, who is also ill in a similar way, and I often trade photos of bad art, so it would be a play on that. When I thought it over, it seemed like it might be too difficult of a project to tackle in ten weeks. In the end, I only included one ekphrastic poem in the collection titled "Dreaming of my Mother's Flowers at a January Appointment."

In the project, the photos that aren't specifically a part of the photo essay are photos of similar spaces and things, but they act more as a breathing space between poems. To some, the space of a doctor's office is visited once a year, maybe a few times more. I see these spaces so often, and I wanted the reader to feel the ordinariness and loneliness and blandness of these spaces. They are uncomfortable, impersonal, full of weird objects, and mostly freezing cold. I decided not to include captions with these photos because of the depth I go into in the photo essay. As well, it is a bit of an homage to Claudia Rankine's *Citizen: An American Lyric*. Her collection includes lots of unexplained art that was later explained to me in a lecture she gave at DePaul this spring. I liked that I had some completely different ideas about the art that she included as compared to her actual intentions, and I am interested to hear the reader reaction to those photos I include in my project.

Q: What are some oddly specific details about your writing process?

I spent most of my time writing in my apartment, but I was almost always in the blue robe that was gifted to me by Oprah that I explain in the first part of the photo essay. Or, I was in my bed with my salt lamps on the highest brightness setting with my lavender candle on. After about 7pm, my eyes become tired from looking at a screen and I can trigger migraines that way. While I draft everything in a notebook, all of my revising and rewriting happens on the computer. The salt lamps and lavender candle help me relax a bit and kept the lighting low. I had two go-to snacks while writing as well: the knock off Swedish Fish from Trader Joe's and/or Trader Joe's everything-flavored pretzel chips. Usually a can of sparkling water too.

I also primarily listened to two albums: the demos of Whitney's new album, "Light Upon the Lake," or Sufjan Steven's "Carrie and Lowell." Both were quiet enough to not be too distracting, didn't make me feel like I needed to always sing along, and generally stayed at a quiet murmur as opposed to the peaks and valleys that some albums can be volume-wise. In the past, I have not listened to music while I write because I typically find it distracting. I found silence deafening while I wrote for this project and I'm still not sure why, but that's most of the reason why I listened to music.

Q: What have you read that you think unconsciously affected your writing?

In the back of the final project, there is a direct list of citations that include what I read specifically for this project. It includes Virginia Woolf, Susan Sontag, Eileen Myles, Sylvia Plath, and Elizabeth Bishop. I also included Judy Blume, Joan Didion, and Audre Lorde. Those were all conscious choices, especially because they're explicitly regarding illness. There are plenty of books that include illness or

talk about illness, but that is not the main point of the text. A lot of time at the beginning of the project was spent reading through texts to see if they were what I was looking: directly about an experience with illness that focused on a individual and discussed daily feelings and life. Plath and Bishop were read more for craft than content.

However, in terms of unconsciously, I think that reading a lot of the *New Yorker* and *Paris Review* has changed my thinking about writing. So many authors are well spoken about their craft and intent, very specific in their ideas and such. In turn, I think that helped me get really specific about not only the intent of my project, but my process as well. "The Art of (Insert Genre Here" interview series in *The Paris Review* in particular helped with this. Bishop, Myles, and so many more just have all of these great lines in their interviews. Reading those is almost second best to having a conversation with the authors themselves.

### Q: What's on your book cover?

My book cover is a pattern of some of the medications I take. Asia Shelton, a friend of mine, designed it. I contacted her because she takes great photos on her film camera usually only natural light, and I had this idea that she could photograph some open and spilled pill bottles next to a stack of my favorite books on a table with the light on them. But, she decided to do something totally different and I ended up loving it. It was fun to work someone who had read my project and then made something inspired by it. How I like to think of the cover now is that it resembles the unexpectedness of invisible illness. From far away, the pills could look like polka dots or a pattern but up close, it's the pills.