

If/Then

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i. As a child, I loved running. I chased kids around the playground, tore across soccer fields, and flew down the winding woodland paths that made up my home with no inhibitions. Action was my baseline. I didn't always get along well with other kids, never quite felt at home in classrooms. I dreamed of being wild – a creature in the woods, free to run and jump and climb at will. Nature didn't scare me. Living in the hills didn't faze me. Feeling that first nip of cold just before a snow filled me with hope.

- ii. The university where I am a graduate student is the hilliest place I have lived in since I left my hometown at 18. It's also small enough that driving to school from my home seems ridiculous—a twenty-minute walk is nothing, after all. It makes you a little sweaty, maybe a little tired, but all in all, do-able. The walk is a way to get outside before and after a long day spent in classes and the library. It ensures a time for exercise in the busy life of students, especially graduate students. And 80 percent of the time, that walk is fine for me, too.

It's that other 20 percent I have trouble with.

- iii. I started having joint issues at 16. It might have been happening before, but I was a soccer player and accustomed to pushing

through. Then it started getting bad. My ankles were twisting constantly—I sprained

them several times a year. I started slowing down at soccer practice, my back and my legs unable to keep up with the drills. Snow days brought me stiff joints and achy muscles I could not understand, let alone explain.

I remember when the issue became a problem. My parents had gone on a vacation, leaving me home alone. I woke up the first morning to a grey sheet of rain, pouring down so hard it looked solid. Not atypical for the area. I got out of bed, turned to go up the stairs, and collapsed. My hip seared with pain, like a lance had gone through it, neatly slicing the tendons and ligaments. I spent ten minutes sitting on the stairs, the pain slowly throbbing into nothing but a ghost of itself. Then I went upstairs, ate, and headed to school.

I was there maybe half an hour before I dragged myself to the admin office. They called my parents. I went home. My hip was so stiff I could barely get in and out of my car. I spent the rest of the day in bed, listening to the rain batter the house and the wind whip the trees, and thought about how very strange this experience was.

I quit soccer not long after.

- iv. As a rule, I'm not very good at reading people. But I have become well-versed in reading the silence of a primary care physician. A one-shoulder shrug and no eye-contact tells you that they don't actually

believe you when you say you're in pain. Two-shoulder shrug, eyebrows raised, maybe an exasperated sigh - this means they've done all the tests they can think of and now they *really* don't believe you. A pair of down-turned lips and lowered eyes are the signs of a doctor who does believe you, and knows they've failed you. A roll of the shoulders and a set jaw means they haven't got it yet, but they are damn well set on figuring it out.

I like to imagine that when a doctor finally tells me what is wrong with me, they'll do it with steady eyes and relaxed shoulders.

- v. There are many types of tired. There's gym tired and kid tired; funeral tired or work tired; traveling tired, annoying relatives tired, shopping tired, world tired. All of these wear a person down, make them slow and sleepy, make them look for a moment to recharge their batteries before getting up and going again. They're temporary tired, a tired that is meant to pass. And then there's Chronic Pain Tired. With Chronic Pain Tired, the recharging time is limited, the electricity keeps cutting out, and the battery won't quite hold a charge. Chronic Pain Tired is a constant weight, a pulling-down of your entire being. It follows everywhere you go, a stalker you cannot shake. A dark force hooked into your spine that slowly siphons out your already limited energy. Everything I do, I do while Chronic Pain Tired. I write a paper Chronic Pain Tired. I read books Chronic Pain Tired. I go to class Chronic Pain Tired and I participate in discussion Chronic Pain Tired and I learn Chronic Pain Tired. And all the while, I am in pain Chronic Pain Tired.
- vi. Imagine that you had 16 spoons. Each spoon represents an equal amount of energy. Make a list of everything you do during the day, from getting out of bed to going to sleep.

Look at your list, and remember that you have chronic pain, so everything you do, every action you take, will require a spoon.

You wake up. You need to get out of bed, but your joints are always stiff in the morning, so you need to take a few minutes to stretch them out. Hopefully you won't fall back asleep doing that (always a risk, since you never sleep well with chronic pain anyways). After five minutes, you finally get out of bed. -1 spoon.

Now you must eat. You could cook a big breakfast, healthy and energy-filled, non-inflammatory, but then you'd also have to do all those dishes and that's too many spoons so early in the morning. So you eat some yogurt and toast, have some coffee, clean up. -1 spoon.

You skip the shower, but you're having a hard time standing today, so brushing your teeth is more painful than usual. -1 spoon.

Time to head out. You decide to drive, because walking costs too many spoons. But parking on campus is full, so you have to park farther away on a hill and walk back. -3 spoons.

You head to class. It's up a steep hill. -3 spoons.

You sit in an uncomfortable chair for an hour that wreaks havoc on your hips and back, all while trying to be engaged in the lesson. -2 spoons.

You've now used 11 spoons. You still need to go to other classes, do homework, study. Eat. Go home. Brush your teeth, wash your face. All with 5 spoons—but will that be enough?

- vii. Unless Professor Xavier is hanging around me, I don't expect anyone to understand that I'm in pain. My disease is invisible, even to doctors. The tests come back fine, which means that nothing's wrong, right? Maybe I'm making it up. Maybe I'm exaggerating. Or maybe medicine just hasn't caught up to all the possible diseases the human body can have. Either way, I don't get documentation. I don't get a disability sticker, or inclusion to a resource center that will help me not fail my classes if I can't get to school. I don't get a service animal that acts as a giant, neon sign that says *I'm sick! I'm sick!* I certainly do not get the benefit of the doubt from anyone.

So I push through. I fake it, and I make it, and if that requires me to spend every free moment in bed, then so be it. At least I didn't fail.

- viii. My life is spent bargaining with my body. *If, I tell it, you let me get through this class, then I'll go home and lie down. Or, I just need to finish this chapter, then I'll stretch, careful and slow, just the way you like. Maybe, I promise you'll get a whole weekend in bed if you let me just get through these two days where I have to walk all across campus for school.*

And of course: *I know I've been sitting in this uncomfortable chair for four hours, taking notes and participating in discussion, but let me get up without collapsing on this stiff hip and I'll take some of our special pain meds before I go to bed tonight.*

- ix. Like many other people in academics, my to-do list is long and never-ending. Homework and thesis work goes on our list, but these are not enough to make it in this program or in this job market. So teaching associate work, research assistantship, volunteering, and building professional development skills

also go on that list. Networking and applying to jobs or future schools goes on that list. Internships go on that list.

My list also includes physical therapy exercises, eating non-inflammatory foods that are expensive and exhausting to prepare, making sure I have enough time to get from place to place in case of a pain flare, guessing how much slack I can afford in case of a pain flare, figuring out the least-exhausting routes between my classes, and reminders of what to say to sound believable at future doctor appointments where yet another doctor will give me a dubious look and ask me where my pain is on a scale of 1 to 10.

- x. *On a scale of scraped elbow on counter corner to literally shot in the head, where is your pain?*

I'd say my pain is more than the quick stab of a needle on blood donation day, but not quite someone shoving their whole foot up my ass.

On a scale of a cat accidentally scratching you to a polar bear using you as a play toy, where is your pain?

I'd say it's right around walking with an anchor hanging off one hip.

On a scale of a paper cut to stage-four lymphoma, where is your pain?

I'd say my pain is not a measurement that can be easily quantified for others to pass judgment on. My pain, like every other person's pain, chronic or not, just is. No one will ever be able to fully relate to my pain, just as I cannot fully relate to theirs. My pain may not be a sweet summer breeze, but it's not an Antarctic snow storm, either. It hinders me in ways I cannot easily explain,

and that is okay. I do not need anyone to understand what it feels like to be in pain all the time, just to understand that *I am*.

- xi. I cannot escape my body; I must bring it with me, and so I must bring my chronic pain. Each day is a constant bargaining of *if, then*. This pain is inescapable. But it is not insurmountable. I am here. I am in class. I engage, I do my work. And every moment, I lead the charge in my war with chronic pain and the exhaustion that is its bedfellow.

If you want to help me win, then stop asking me to quantify my pain and start asking me what I need to succeed.

Lindsay Mixer is a graduate student in Public Sociology. Her research focus is on human sexuality and disability studies. Currently, she is pursuing research on fanfiction and its influence on sexual development. In the future, she would like to study how sexuality intersects with various disabilities, both mental and physical.
