Do You Hurt Here?

By Jennifer Schneider Malamud

Therapist: Why do you call your feet Lavender and Sashimi?

Me: My brother, Jonathan, told me to pick one name. I picked Lavender; it relaxes me.

Therapist: And Sashimi?

Me: Jonathan wanted to name my right foot Stephanie. I didn't like that. I knew a girl called

Stephanie who had a curved bone.

*Therapist: So, Sashimi?* 

Me: He likes sushi.

"I'll just call it my imaginary friend," I say the day that I'm diagnosed with fibromyalgia.

Through the hospital window, the falling leaves of late September turn as red as the eighteen pain points in my body. The rays of sun reflect upon my glasses, and I close my eyelids. It feels reassuring to realize I'm not crazy; that my pain is not an invention of a hyperactive make-believe.

Lasonia, the nurse practitioner, looks at me from the computer, while my mom stands in the corner of the blank walls. I sit on the bed hoping the sheets will swallow me along with my dizzy neurons and painful bones.

I remember yelling at my feet for causing me pain, as if they were evil beings that existed outside of my body. I remember the self-hatred that followed: Who will want to be with me if I can't walk? My therapist says that I cannot personify my body anymore. Lavender and Sashimi turn once again into my left foot and my right foot.

"They are my problematic children. The right one is the moody teenager that passes out drunk every weekend, while the left one is an introverted piece of shit that never causes a fuss until it sends sharp acidic shocks up my calf."

You are funny, my physiotherapist used to say.

You are hilarious, echoed the nurse practitioner at the fibromyalgia clinic.

For sure, I thought, I'm a clown with a crab snapping its claws at my calf, and an acidic mouse spasming up and down my left arm.

My nose scrunches in search of lavender perfume. I'm not allowed to wear creams or fragrances; they make some patients dizzy, but it doesn't matter, because I feel dizzy all the time.

"Are you dizzy, tired, or fatigued?" *All of them*. By now, I know that there are different ways to feel lightheaded, but if I'm not allowed to personify my disease, I cannot distribute nicknames among my symptoms.

At first, I used lavender aromas as a placebo perfume to breathe and relax when stressed. Soon, lavender turned into my addiction, and I yearned for some lavender seeds to chew in my mouth like smelly tobacco. My lungs revolt at the idea and sing in my chest: We are healthy!

Remember the other day when the doctors gave you a spray medicine during one of the tests, and then you became dizzy, and your heartbeat ran with tachycardia? Do you want your torture to be in vain?

I breathe and answer my lung: You are right, my love, you are healthy, and so are my muscles and my skin. So is my tendon, even though the first doctor I consulted said I didn't have one in the first place. My orthopaedist said that's why it hurt to walk, and he doesn't need any medical tests to confirm so, because he has a university degree that proves he wasted nine years of his life studying the human body.

Therapist: Why are you so fixated on this young man?

Me: I'm not. I just want to figure out if he's just being nice. Either way, he probably isn't into me.

*Therapist: And why is that?* 

Me: I mean, why would he be? He was a swimmer and won a bunch of gold medals. He probably wants to be with someone who can walk down the stairs.

Therapist: You won't be sick forever. Plus, you have the right to walk at whatever pace you choose. If anyone doesn't wanna walk beside you, then they aren't worth it.

Me: I guess I'm just jealous. Maybe if I can spend some time by his side, I'll become as healthy as Eli.

You promised you would text me on Tuesday, and you did. I made you promise because it was the 21st of September, and I wanted you to *care* about me on my birthday. I wanted you to help me forget about the needles and electroshocks of the medical test. Eli, I wanted to remember only your giant frame and soft words.

I texted you again and you said you would call me after class. You lied, or maybe you forgot. I messaged you afterwards to tell you about a new alternate reality amusement park I hoped you'd invite me to, and my new diagnosis. I waited for your reply while suffocating inside the blank and odourless hospital walls. You left me on read at the end of both conversations, but I don't mind. You probably want to avoid hearing about any misfortunes, and I know you rarely talk on the phone, unless it's about something "urgent or important." I recall the words of writer Juan Rulfo: "No one walks in search of sadness."

We spoke on the phone on Friday, while I packed my suitcase to come to the hospital—I asked for a chat, and you said yes. I told you about the incident of my injections: It was September 16°, Independence Day here in Mexico, and I couldn't stop crying from the pain. So many spasms racked my left arm that I couldn't hold it upright. My mom and I drove in the car for an hour before I could get the injection. The pharmacy near my house was closed due to a COVID case; the other one we rushed to had fifteen people working in it, and none knew how to help me. Finally, we came upon a little pharmacy on the outskirts of the road, and the guy behind the counter said he knew how to administer an injection. The bathroom had a dead cockroach, a ladder propped up next to the toilet, and nothing to lean on. My mom opened the restroom door to make sure he would not harm me. I lowered my pants with my good arm and the guy jabbed my butt with the needle. A rough hand cleaned the blood with alcohol. My jeans scratched the band-aid as I pulled my pants up, while the molten lava traveled from my rear into my tendons. My tears flowed through the scorching pain for the next twenty minutes.

After I finished the story, I asked if you wanted to talk about anything—how are *you*? You said, "I have nothing to share that can compare to your trauma." I thanked you for your time.

I know why I like you, Eli. You are kind and I love the meaning of your name, "God is with us." I like you since you let me hide in your room, while your sister complained about her draining day as a doctor. I asked if *you* had any complaints, and you said "none." *I wish I could say the same*. My ears could no longer endure the word doctor—your sister then seemed the eternal practitioner, and I, the eternal patient. At the time, I didn't tell you that they take my blood every week, but you still lent me your chair and taught me how to play your car-racing video game, without commenting on my trembling palm.

"Depression is my passion," I joked later in the evening while we laid on the plush leather couch. You laughed, I laughed, and so did everyone else in the room. I recalled the lyrics of a song by Tyler the Creator, "I wonder if you look both ways when you cross my mind," and was glad to have you as my crush. I love the infatuation you can feel with a near-stranger, elated at the uncertainty.

You showed me your scar, and I wanted to touch it with my fingertip. I almost did, you almost let me, but then I pulled myself back with an invisible string and chuckled. You were hurt, I saw it in your eyes, but you stood too close and too kind, and I'm just a girl who dances in her room to avoid crying, and why would you—who can swim miles in the river—pay any attention to a girl whose nerves and immune system fail her? That's what crushes are for, to play pretend.

Therapist: Sad but pretty...where did you get that from?

Me: It's from this book, Boobless Mammal. The grandpa of the protagonist tells her that even if she is sad, she still looks pretty.

Therapist: Like good marketing, right?

Me: I don't know...I guess people see me the same way, but I hate everything lately. I swear, I don't believe anyone that calls me pretty anymore. They are all fucking hypocrites.

Therapist: Maybe they just think you are pretty. Maybe deep down, people still think you are the same person, with or without a sickness.

Me: I swear, from now on, the only compliment I'll take is "you look super healthy." I'll kiss the first person to tell me that, on the mouth.

I gawk at the summer sun through my window and limp towards my bed. I'm jealous of everyone who gets to experience June in bliss. While cempasuchil flowers open throughout Mexico City, I slowly lose my bodily functions. I wish I could see wrinkles in my arms, if only to look the age I feel.

I send a text message to Daniela to ask if she can talk. The phone rings and I answer.

"My body is self-destructing. Everything hurts. I'm tired and sad all the time. You were so young when you got cancer, only thirty years old. And you published a book, you teach dancing classes, I just want you to tell me how to survive this."

"I lived on antidepressants for a year," she says. "Just know that, from now on, whenever you leave the house, you will have to take your wallet, your keys, and your auto-immune disease."

I read Daniela's book *Boobless Mammal* after hosting her as a panellist for a podcast on mental health. I remember the phrase "sad but pretty." It rang especially true after my first diagnosis with antitethase syndrome, when suddenly everyone in my life seemed to find me gorgeous.

"I wish everyone would stop lying to me," I told my therapist.

"I don't think the cashier at the coffee shop was lying when she said, 'hi cutie,' or the guy you seem to like so much when he called you 'queen.'"

After that, I began repeating "sad but pretty" like a mantra, and when my friend Mijal said that she always forgot about my sickness because I always looked so happy, I felt like a better actress than Meryl Streep.

"You have luck with all lottery like prizes," said my mom. "It's no wonder that you have an immune disease they only diagnose to one in every million people."

"Of course, Mom, I won the lottery."

I yelled at my mom; she yelled back. We both apologized and said I love you. She claimed to feel my pain, and I told her not to diminish my struggles.

"I misspoke," she explained. "I meant to say that your pain makes me suffer as well." Well, it's good to know that I'm still capable of being loved.

Therapist: So, you say you stopped talking to some of your friends?

Me: Lately, I just talk to people whom I feel comfortable around. This pain...I can't turn it on and off. I just hang around people who are patient with me.

*Therapist: Do you feel like you are losing friends?* 

Me: No. I love my friends. I just wished I could care about normal stuff. It's like I'm suddenly eighty. I'm not supposed to have muscle pain at twenty. I'm supposed to get drunk and make out with a random stranger.

Therapist: I don't think you'd do it even if you were healthy.

"Do you hurt here?" asks Lasonia, the nurse practitioner touching my left shoulder.

I hiss from pain and think, do you pronounce your name like lasagna?

We stand next to the hospital bed in the fibromyalgia center. My sock-clad knees point towards the door as I search for an escape. Purple shadows still gnaw at my shoulders from the scorching sweat test.

"Yes."

"How about here?"

You say Lady Gaga and Morgan Freeman have fibromyalgia, as well?

"Yes." My arm trembles and my vein pulses from the six vials of blood the doctors sucked out of me this morning.

I breathe slowly through my nose. Lasonia now touches my right shoulder.

"And here?"

Do you enjoy playing Where's Waldo with my body? Let's see how many spots on this girl's body we can turn red. Yes, Lasonia, it hurts there. It hurts all over. I know it's your hand, but I feel like you are touching me with a brick.

I know my feet will not carry me to the door fast enough to avoid the next touch. Perhaps, if the door teleported towards me... I could have exactly what I hoped for, just once.

Me: My doctor...he said my immune system was attacking my muscles, that we had to lower it.

Therapist: And how did you react?

Me: I cried. I told him I'd rather never walk again than die from another disease...I'd rather spend the rest of my life in a wheelchair instead of strapped to a hospital tube.

Therapist: That is a disturbing thought. What did he answer?

Me: That I had to take chemotherapy pills, that my lungs would also be affected otherwise.

Therapist: And how about COVID? How will you manage that?

*Me: If I get infected, I'll be hospitalized.* 

In August, I went to a rheumatologist for a second opinion. Summer ended and I hoped my nightmare would end along with it. Dr. Flores asked me horrible questions: *Do you have mucus in your eye? How many times a day do you pee? If you are sexually active, has your sex* 

drive decreased? Does your poop come out green or watery? Have you noticed if those chipmunk cheeks are any more bloated?

He then had me lay naked on the bed with a paper-thin blue robe covering me. Dr. Flores made me prop my feet flat and I became certain he could see my panties. I tried to put the robe over my legs, but he separated my knees, and the physical exam began.

"He is an internist, that's why he conducted such a thorough physical examination," I heard my dad say through the sobs on the car ride home.

"He had you waiting outside the room, Norbert. He didn't let us use the bathroom even though we were on the road for an hour and a half," disputed my mom.

I kept on crying, recalling the physical examination. Dr. Flores touched my legs and my arms, putting pressure on all points in my body until I yelled for him not to touch me anymore. I thought, *please stop, the pain is too much, stop touching me*.

Then, Dr. Flores said, "close your eyes, I'm going to use different stimuli on you, and you have to guess what it is." I felt a silky, tingly touch over my right leg—it's a paintbrush.

Then, I felt a sharp point piercing through my skin into my tendons—it's a needle. My whole body turned red like the photograph of my calf's ultrasound. Paintbrush, needle, paintbrush, needle. The touches turned my skin into a volcano of pain, with guesses of the torturing devices wandering my neurons.

"Give me your hand," Dr. Flores ordered, as a volcano of pain turned my skin from rock to plasma. My lungs shouted, *make him stop, make him go away; I beg you*.

"Can I see the needle, Dr. Flores?" asked my mom. Dr. Flores showed it to her, and she nodded. I wanted to see the needle as well, to figure out her nod, and why she pursed her lips shut.

"Why did you come here?" asked Dr. Flores afterwards.

My mom attempted to speak. A binder overflowing with my medical records sat on her lap.

Dr. Flores shushed her with his sweaty palm: "I asked the patient."

I wondered if he'd washed his hands before he conducted the physical examination.

"I just want to feel better."

My dad paced outside the walls asking us to speak louder, as he attempted to hear through the bells of the Chinese spa on the bottom floor.

"I need to know right now if you will work with me."

I've never before felt pain and humiliation at the same time. I never want to see you again.

"I will consult with other doctors and get back to you, Dr. Flores," I said.

The needle turned out to be a ruler.

Me: I have known Dalia all my life. She is a childhood friend from Peru. I remember having sleepovers at her house, and anecdotes of how she used to bite her thumb until it became flat...

Therapist: It must be hard then, knowing that her dad died, especially when you are experiencing a similar kind of physical pain.

Me: I don't know. My mom got upset at me over how emotional I got. Said I didn't even know the guy...I know Dalia though, even if we've lost contact.

Therapist: I think your mom is right. It's okay to be upset, but you can't stop your life because of other people's problems. You are dealing with more than enough, at the moment.

I ride in Mijal's car towards the cinema. She asks about my childhood friend Salomon, who was visiting from Queretaro next week to check on me after my time hospitalized.

"He's not coming anymore, his uncle died. He had cancer; the chemotherapy didn't work. He was in so much pain that he asked to be put to sleep. Salomon is going to Peru for the funeral. I was a friend of Dalia's, the daughter. I can't even imagine what it's like saying goodbye to your dad, knowing that he asked to be sent away."

Mijal's curls bounce when she turns to look at me. The rock ballad covers the night with a harmonious blanket and the lyrics "we are the warriors..." ring like an omen in my ear.

"I know what those hospital visits are like, my grandmother had cancer," replies Mijal.

I think of my own grandmother laying next to a red wig while the cancer travelled from her breasts into her bones, how that was the last time I saw her because seven-year-olds are not allowed hospital visits. I recall how I didn't find out my uncle had prostate cancer until I turned twenty.

I think of all the things my family omitted and the things they couldn't save me from:

A two-year-old interned in the hospital, clutching a knitted teddy bear, after vomiting all over her room at two in the morning.

A nine-year-old with electrodes all over her head-her hair all sticky from the adhesives—trying to sleep while a camera films her brain and doctors whisper that no one convulses when sleepwalking, that those types of night owls have epilepsy.

A sixteen-year-old with a fever and a light ankle sprain, getting injections six days in a row–every two months. The blood tests come out negative, yet simple flus lay her down for a week, and *it's* such *a shame that this time it coincided with her dance injury*.

After turning twenty, limping on to an orthopaedist, no one knows what I have; a negative MRA, blood tests, a CPK of 900, a doctor's omen—your body is self-destructing—, an auto-immune condition, a jumping vein, a physiotherapist claiming that my muscles are weak since I lost so much fibre tissue, spasms in my left arm, injections in a dirty bathroom while crying from the pain—two weeks at the hospital, you shouldn't have pain anymore, we have your condition under control. The new routine of having a body in constant pain. Living with ankle-clutching crabs and plasma tendons.

A humiliating doctor, needles and electric shocks exploring my body in an electromyogram, an hour and a half in a hot room at forty degrees Celsius with yellow powder turning purple from sweat to induce a fever, a nurse pressing the pain points in my body—the sweat test shows that your nerves are not processing pain signals correctly—a fibromyalgia diagnosis with Morgan Freeman and Lady Gaga.

At least my pain has a reason. I thought I was crazy.

Mijal knows what the hospital visits are like, but I empathize more with the patient. I don't know the pain of cancer or of saying goodbye to your family, but I do know how to live in a perpetual state of pain. I called Mijal when I was crying the other day and I don't want her to hear me complain anymore, so I say nothing.

We get into the cinema line late. Our friends must be waiting.

"Eli called; he wants to know where we are."

I see you before Mijal does, while carrying the movie tickets I just purchased. I say hi by pursing my lips and placing a peace sign next to my cheek. You smile, stretch your arm above your head, and wave once. You wear a pink tie-dye psychedelic shirt and I notice you got a

haircut. I'm afraid to say anything. Maybe I opened myself too much during our chats at the hospital; maybe you don't want to talk to me, and are just being nice. I adjust my jeans and the tank top I wore only because I knew I would see you. Subtlety is not my forte. I wonder why no one has commented on my crush. Perhaps I'm not so obvious, or they don't want to be mean.

You open your arms wide and come in for a hug.

"How did it go? Wait...you're here, so surely everything is okay."

Your eyes remind me of the sand of the Peruvian beach on a sunny day. They are dark brown, and your skin is golden. I look pale next to you, and I pray that you can't see the purple bruises colouring my skin a lavender hue. They travel up my leg to mingle with my bluish veins.

I'm attracted to how healthy you look. If my balance gave out, I feel like you could carry me. Maybe you are strong enough to fight against my own white cells, or to snap my tendon like a rubber band. A song by Residente says, "from near or afar you boost my immune system," and I want that type of love, the kind that cures illnesses. I use my crush on you as a coping mechanism—hopefully that doesn't upset you. To be honest, I don't know if I would like you if I was healthy, but that chance disappeared like the ice in the Arctic after the ozone layer burst. Now, I waste days thinking about someone I will eventually forget.

"It was torture," I answer as you watch me struggle up the stairs. *Do you know you met* me at the worst moment of my life?

*Therapist: So, at first, you didn't think your pain was important?* 

Me: My mom was dealing with her own health issues. She got a shoulder operation about twelve years ago and she hasn't been the same ever since.

Therapist: So, your thing didn't seem that relevant in comparison?

Me: I've had sprains before. I thought it was the same thing.

Therapist: You have to learn to take care of yourself.

Me: I had to take care of my mom. She couldn't even lift her arm enough to shampoo her hair. At one point we thought she might lose the arm.

A shout pierces my room.

"HELP! HELP!"

I wonder what my mom might want this time. It's early February, before the pain spreads from my right foot up my arms, to dizziness over my head, and tremors over the rest of my nerves. It hurts to walk down the stairs, but I still haven't needed to drag my feet, because my left calf lost its blood circulation. It's before I've had to use a wheelchair, or learned the meaning of a rheumatologist; before I've had to spend each Friday getting a needle to leech five vials of blood from my arm.

For the moment, acid shoots up my calf as I limp towards my mother's room, expecting her to ask me a favour.

"What happened, Ma?"

I find her laying down on her bed with her rear exposed to the cold air and a red splotch on the panties that sit next to her. I have never before seen her so fragile.

"I just called my gastroenterologist," she says with a voice originating from the afterlife.

"I need you to tell your brother to drive me to the hospital, and I need you to tell your father to meet me there."

I help carry her off the bed and put her pants on. I'm not aware that in a few months, I will need to ask my father's help to put on a t-shirt. I knock on my brother's door, I call my dad, I

help my mother to the door, I limp through my ankle pain, I fill a bucket with hot water and two spoonfuls of salt, and I finally bathe my traitorous ankle with the balm. I'm able to breathe through the pain for the first time in half an hour.

I call my aunt after a few months have gone by, to tell her that I'm afraid my family's patience will run out, and they won't wait for me to walk anymore.

She answers, "they love you too much for that, they will always help you and put your needs first when they need to."

I recall the phrase we accept the love we think we deserve, and I tell her my mom's story to show her that I would do the same for them.

Therapist: When I was twenty, I got into a car accident. I was immobilized for a year.

Me: So, you, more than anyone, understand how I feel. I don't feel attractive. I feel gross and tired.

Therapist: For sure. There's nothing cute about sickness. It's a tiring ordeal. There's nothing romantic about it.

Me: Yes. Fuck John Green.

Therapist: Fuck John Green.

In A Year of Rest and Relaxation, the protagonist wants to sleep for a year to wake up refreshed. The new bluish pill I got prescribed to treat my fibromyalgia forces me to sleep for sixteen hours a day. I think about John Green, and my hatred for him after my first diagnosis with antisynthetase syndrome. Of fucking course this cute functional guy is going to see through my inability to walk properly down the stairs, my bloodshot eyes, and my perpetual frown and

think: I want to have health-jeopardizing romantic trips with her. They say that time cures all ailments. Now, I no longer hate John Green, but the protagonist of this book I haven't even read.

I swear that people who don't have any problems invent them. I'd rather read about fake romance than about a girl who complains just for the fun of it. I will never complain again once I go into remission.

I wish I could have normal problems.

Phoebe Bridgers sings, "the doctor put her hands over my liver, she told me my resentment's getting smaller." My family-friend, Esther, told me that doctors are a mafia, and I thought she was crazy because she enjoys healing crystals and manifesting through tarot cards.

After consulting with eleven doctors before getting a diagnosis, I believe she is the sanest person I know.

The doctors didn't believe me when I said the treatment was not working, that I still felt pain. I thought I was crazy.

My mom and I ride in the car, away from our weekly visit to the hospital. We fight because we don't know what else we can do. The city looks lifeless, like God puked iron-clad buildings in the place of foaming green leaves.

"I never thought you were making the pain up," says my mom. "But, for sure, I thought you were exaggerating." She huffs. "I could never have imagined something like this."

If nature still inhabited the city and I jumped out of the car, the resulting pain would let me hide inside a rain-soaked blanket.

"At least I know I'm not crazy. At least my head still works."

Me: My mom organized a prayer in my name. My whole family cried in front of the altar.

Therapist: Maybe it was a cathartic moment.

Me: You know...the other day at the doctor's, I was cursing my sickness, and my mom told me to stop, that I couldn't curse, even when I was sick. My religion says that when you're ill, if you want a change in fate, you have to give to others: time, money, doesn't matter...

Therapist: Maybe that means that, even when you're sick, you still have something to offer.

"For each of us their shame, but for everyone joy," said Peruvian author Alfredo Bryce Echenique. I repeated that phrase when my mom pushed me on a wheelchair. "I don't want *you* or anyone else to see me," I said hiding inside my hoodie, "I just want a vacation inside the body of someone young and healthy."

I saw the people on the street: some overweight, some asking for alms, and others shallow as empty seashells. Unaware of their stories, I thought they saw a healthy girl, taking away a deserving person's wheelchair. I decided, then, that if given the chance, I would not trade my diseases and my two diagnoses for another ailment. It is *my* immune disease and *my* fibromyalgia—I would not have the energy to get accustomed to another's struggle. Even pain becomes routine.

Once you begin consulting doctors who love to hide your blood in needles, you never stop. Living a never-ending nightmare of conversations with all-knowing professionals in laboratory coats, I imagine running away to live on the beach, smoking pot, falling in love, and chasing after butterflies. At first, the road is plain and simple, but as I begin to walk on the sand, crabs clutch at my ankles and seashells scrape at my tendons. The sun blinds my eyes, leaving the landscape as blank as the walls of a hospital room. I step into the ocean's healing liquid, turning my pain from plasma to molten lava, and swim with Eli between the waves.

The idea that nothing lasts forever used to scare me, but if nothing good can last, that means nothing bad can last either. Some people say that pain is what makes us human. In that case, I, more than any athlete, am a prime example of the human race. Failing lungs, failing tendons, failing muscles, failing skin.

If pain makes us human, you should all feel jealous of me.