

## The initiation: a patient's story

■ Cite as: *CMAJ* 2023 April 17;195:E555-6. doi: 10.1503/cmaj.230026

I stare at my feet poking out of the thin cotton blankets. My right leg is wrapped to the knee in a blue cast and propped up on pillows, my left leg lies to the side, numb and tingling. I channel Uma Thurman in *Kill Bill* — “Just wiggle your big toe.” I concentrate, sending all of my will and energy to the task. Nothing happens. I sigh. It's been over a month and I've done everything I'm supposed to, why isn't it working?

I take a few calming breaths and remember my neurologist's warning: “You're going to need a lot of patience.” “Easy for him to say,” I think. Instead of following my thoughts down a now familiar rabbit hole of despair, I turn my head toward my roommate (I'll call her Mary), looking for conversation, but she's in surgery. The faded pink curtain that divides our room is open, revealing furnishings identical to mine — an adjustable hospital bed, a nightstand, a long, thin table that slides over the bed, a melamine wardrobe in pink and toothpaste green, and two chairs for guests. She has a fleece blanket on her bed and a real pillow. My half of the room remains institutional — it all happened so fast. There was no time to pack a bag.

I call my husband to hear his voice and say goodnight. The conversation is short, neither able to speak our minds in fear of worrying the other. We are two ships navigating a storm in uncharted waters, trying hard to keep each other afloat. “I should try to sleep,” I say, “I love you.” “I love you too. I always will,” he replies, his voice catching.

The clock on the wall reads 10:25 pm. I turn off the light and let my head fall back into the pillow, counting each tick of the second hand. The folded-up wheelchair at home flashes in my mind and I scold myself for being so stubborn, for refusing to use it despite my husband's pleading.

As much as I hate it, I must make peace with the chair and accept that it represents freedom and movement, not limitation and failure. So much has spiralled out of control lately, I know I've been clinging to an unsustainable reality. In a way, this hospital admission is a much needed lifeline, a chance to figure things out, even if it is humbling and unsettling to be here. I vow to make the most of the situation, to prove that I am not out for the count, that I will walk and work again, that I will learn to live with this autoimmune monkey on my back.

An alarm jars me awake, my heart racing. I sit up and the pull of tubing stuck to my arm reminds me where I am — alone in the alien world of a hospital ward. I realize that the source of the rhythmic and irritating beep is the IV pump next to my bed. The plastic bag of saline hangs limp and empty. Nothing to worry about.

I close my eyes and try to ignore the piercing beep ... beep ... beep. “Aren't hospitals supposed to be quiet?” I wonder, taking in the shrill echoes from other machines in the ward along with calls of “Nurse! Nurse!” The squeaking of the nurses' sneakers speeding from one room to the next completes the cacophony.

My nurse rushes into my room. Her face is flushed and her hair is dishevelled. I watch as she changes my IV bag, silencing the ubiquitous noise. Strands of grey pepper her brown, shoulder-length hair, and laugh lines are visible around her tired eyes. We make small talk for a moment until, down the hall, the beeping starts anew. “I better get that. Go back to sleep.” I glance at the clock — it's 12:35 am.

*In my dream, I'm walking along the beach with my husband. It's a sunny day — waves lapping rhythmically on the shore. The warm white sand massages my feet and fills the spaces between my toes.*

*“I'm going for a swim,” I say, splashing into the water, my cheeks sore from smiling. The beach fades. Now we're sitting in a medical office. My legs feel like they are under attack by a colony of fire ants. The neurologist explains that my body is attacking itself, eating away at my peripheral nerves. This is why I've been feeling weaker and why I keep falling. He believes I have a rare autoimmune disorder, chronic inflammatory demyelinating polyneuropathy. “Most people recover with treatment,” he tells us, sounding genuinely sympathetic. The dream shifts again. I'm in my bedroom, sprawled on the floor. My walker lies next to me, no longer enough to support my weakened legs. “I'm calling 911,” my husband says. “But I'm only wearing a t-shirt and underwear!” I protest. Again, the scene fades. I'm lying in a hospital bed in a room full of commotion.*

Blinking, I realize I am awake and the pain in my right leg is excruciating. The overhead light is on and the clock reads 3:15 am. The curtain is drawn and Mary has returned from surgery.

“Mary, do you know where you are?” the nurse asks.

“I'm on a date!” Mary slurs.

“No, Mary, you're in the hospital. You had surgery and it went really well.”

“Did I?”

“Yes, so you're going to rest now. Just lie back, no need to struggle.”

“Get away from me! You're just as bad as the vampires! I know your games!” With that, Mary starts cackling like the Wicked Witch of the West.

“Mary! Don't rip out your IV ... . Oh there it goes. I need a hand in 28-D!” The nurse runs into the bathroom, grabs a handful of towels and catches my eye. “Sorry about this. Sometimes the anesthetics cause delirium. She'll be back to normal soon.”

Sometimes this happens? She sounds really different. Will she really get back to normal? Did the same thing happen to me? My mind is awash with questions, but I don't want to disturb anyone to ask, my inner turmoil doesn't compare with the crisis behind the curtain. My dependencies are already legion, I don't want to be considered needy.

Silence returns to our room, and with it, the pain in my leg. I call out. "There, this will help quickly," my nurse says as she attaches a syringe to one of the ports on the tubing of my IV. A wave of relief washes over me and then nothingness, broken by the shrill, insistent IV pump alarm. I squeeze my eyes shut and clench my jaw. Mary is snoring softly, but for how long?

My nurse glides into the room a moment later, casting a glance at Mary's sleeping form on her way through. "You're getting a hell of an initiation to the ward. Tomorrow night should be better.

I'll give you an insider tip — sleep whenever you have a quiet moment. You're here to rest after all."

*Tomorrow night?* She said it so plainly — but then, why shouldn't she? My neurologist already told me I'll be here until the cast comes off. The break, he'd said, will set me back. "What happened to recovery?" I wonder, "When will I return to work?" The initial week off I requested a month ago now seems like a pipe dream. My identity hangs in the balance, I do not want my story to be one of pity, sadness and unfulfilled potential. I feel a growing empathy for those whose illnesses require frequent admissions — is this my fate? I want to scream and wail. The inevitable loneliness of the coming weeks washes over me. I know that my husband will stay by my side and bring me books and small tastes of home, that friends, family and colleagues will visit, but who will really understand this experience? I look up at my nurse, recognizing a

potential ally, someone who won't balk at the many small indignities of my situation. "I guess we're going to become buddies, then," I say, forcing a smile.

"Stranger things have happened." She winks and slips from the room.

The early sun streams past the heavy curtains, illuminating the clock face. It's 5:30 am. "Today will be a better day," I think, as my eyes become heavy and I give myself over to total exhaustion.

### **Gwendolyn Harwood MA**

Georges River, NS

This article has been peer reviewed.

**Content licence:** This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC-ND 4.0) licence, which permits use, distribution and reproduction in any medium, provided that the original publication is properly cited, the use is noncommercial (i.e., research or educational use), and no modifications or adaptations are made. See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>