# WHOLE PERSON CARE

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## **DROP OF INDIGO DYE**

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he dreaded waiting room. I'm surrounded by the typical silver-haired patients with finely creased skin. *I don't belong here*. Intrusive thoughts creep into my mind. The burden of waiting is released when my name is called, and they usher me into an exam room. Near the end of my appointment, my specialist pauses. I look up.

"Your right upper eyelid is drooping slightly," he observes. His eyes don't meet mine.

"Could it be from not having enough sleep?" I inquire.

"Unlikely," he responds. I shift my weight uneasily in the stiff maroon exam chair.

My head spins. I rush home to figure out when this ptosis began. *Could it be myasthenia gravis?* I can hear a tiny voice in my head as if my brain is somehow whispering to me. I don my doctor's hat. *Duration doesn't fit*, dismissing the idea. It's as if I'm in conversation with myself. *Dyspnea worsening with exercise. Weak upper extremities – despite lifting weights for years. Decreasing stamina, yet no answers despite a battery of tests.* My brain rattles off everything that is wrong with me.

I shake off these thoughts before fear pierces my soul like shards of glass. I slip into my weathered physician armour and compile a list of symptoms to share with my family doctor to make the most efficient use of my upcoming visit.

Before she's done eliciting the history, I catch her eye and implore, "I need this sorted out. I'm worsening."

"Yes, we definitely need to," she declares. "Let us order some labwork and imaging. I will also fire off an urgent referral, too." I melt with relief hearing those poetic verses. "I've got you, Aisha. If we don't find answers, I will find someone smarter than me who can!" she quips with a coy smile as she slips out of the room.

I'm shocked at how quickly the neurologist's office calls me for my appointment. Guilt prickles my skin. My patients wait weeks to see me!

The neurologist's office is nestled in the same russet-coloured building perpendicular to the hospital as my ophthalmologist. This waiting room has grey-washed oak laminate floors, crisp white walls, and floor-to-ceiling translucent windows. An orchid graces the receptionist's desk. I'm the only one waiting in this room.

He ushers me into his consultation room. He appears much younger and taller than I imagined from reading his notes over the years. His eyes emanate kindness. "How is work?" he asks casually.

"It's fine," responding politely. I'm afraid of revealing how work is bogging me down. After a thorough examination, he reassures me that it's normal. I doff my doctor's hat momentarily so that I can absorb what he's saying without overthinking. "I'm not sure if you saw my MRI yet... I just had it done a few hours ago." He nods, returning to his mahogany desk and pulls up the images onto his computer, perched off to the side, with its screen in full view for patients.

I imagine seeing my pristine scans, just like my previous tests. I imagine he'd reassure me there's nothing to fret about. I imagine I'd return to work, blaming burnout as the root cause of my billowing symptoms.

My eyes widen as the image pops up. I don't need the radiologist's arrow to tell me where to look – the opacity glares at me. My body stiffens. Silence thickens the air. "It doesn't look good," he starts. I'm pleasantly surprised by how well he's breaking bad news. And as if he could read my mind, "Your ptosis is unrelated." *Cancer*. My brain throbs for my husband's support. I cling to my physician armour, letting its stiffness hold me instead.

"What's the next step?" I croak. Damn! Why can't I ask an intelligent question?!

"I will refer you to the neurosurgeon. He is very good." He pauses again to give me time to process. "You're lucky you got the MRI. It picked up this incidental tumour early." He pauses again. "Please reach out with anything I can help you with," he says, folding his hands kindly.

"I appreciate all that you've done and taking the time to see me." I can hardly stave off the tsunami of grief, on the verge of breaking the levee. I sail back to my car and call my husband. "I have brain cancer!" I wail. This diagnosis stuns every cell of my being. I lean further into salah (prayer) to find my way through this thick fog. I find reciting verses from the Scripture offers solace. Subhanah-rabiyal-al-'ala (Glory is to my Lord, the most High) as my forehead graces the ground, in child's pose. The glow of spirituality broadens my perspective amidst the abyss. Everything that is happening is meant to be. This world is but a test. Don't despair, my brain soothes me with spiritual teachings.

"What's wrong, Mom?" my youngest teen says one bright but frosty day after school. Her brows furrow.

"Uh...nothing," I stammer. "Actually, I am feeling sad." My back straightens. "There's something I need to share." I gesture her over to the family room. Beams of the afternoon sun tickle our skin. We sit on the couch facing our yard, blanketed with snow, tall pines on one side, junipers caressing our deck on the other. "You know how I've been feeling weak?" I share slowly as I draw in a breath.

"Yeah! You've lifted weights for years, but your arms never get strong!" she teases. My muscles tighten at her astute observation.

"You know, I've had this for years... maybe it's my superpower," I retort. She gets this reference. We're both Marvel fans. I soak up courage like Wanda Maximoff to break this news to my other teens. I find my son having a snack in the kitchen.

He asks pointedly, "Is it cancer?" My heart leaps into my throat. *How did he know?!* I nod. He continues, "Which organ?" He lands another arrow right at the center of the target like Hawkeye. Hearing my reply, his eyes well up. I swoop around the marble island slab for a tight embrace.

And my eldest? She keeps scrolling on her phone. A tiny teardrop emerges as she desperately distracts herself, trying to evade eye contact. *Kindness to family pleases God*—another spiritual reminder bubbles up to my conscience. "No matter what, I love you," I offer. Her head melts onto my shoulder as we both weep.

That night, my husband is restless. I touch his shoulder delicately and whisper, "We need to prepare for the worst. I'm ready to proceed to the afterlife if it's in my qadr (God's divine plan)." Since becoming a physician seventeen years ago, performing heroic measures, I vowed never to prolong my life.

"But I can't lose you. I'm supposed to die first!" His body trembles.

As spirituality allays my sorrow, my husband turns to family. His brother, a cardiologist in the US, offers, "I don't know much about cancer treatments, but forward me the images. I'll get my friend to look at them." The American neuro-radiologist quickly gets back to us. "It's likely low-grade glioma, situated where the neurosurgeon can easily access for a biopsy". *Alhamdullilah* (Praise be to God)! Gratitude emanates for my huband's family navigating us through this. My sister-in-law, an internist, checks in on me, too. *How I wish I had done the same when she was fighting cancer*. I sense genuine patience in listening to my whole story. As I share, the pressure eases off my chest. I can breathe.

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One evening, as I'm finish up charting, I receive an unexpected call from my family doc. "I received the consult letter from your neurologist. I'll take care of the tests to rule out mets," there is a pregnant pause. "How are you and your family coping?" I reveal how I'm drawing strength from my faith. She offers, "I'm here for you, too, walking alongside you on your journey." Her words touch me. They ebb down my synapses and reverberate throughout my body. Her commitment envelopes me. My glioma has diffused for years, like a drop of indigo-blue dye in a tall, clear glass of water. It will continue to do so. Indefinitely.

I find myself peering out of the car's passenger window to see the towering cinder block building with neat rows of windows juxtaposed with sleek white steel and glass curtain façade. Its sea-green windows twinkle in the morning light.

"Did you know I was born here?" I turn to my husband as he parks. "My mum had to stay here for weeks postpartum. Can you believe I'll only be in here for just two days after major surgery?"

We find our way through, through a labyrinthine set of corridors, to the surgical registration and join a serpentine line of patients waiting for registration to open. I feel myself slip into the sick patient role as the seconds creep by. Finally, it's my turn at the registration window. I straighten up and don my façade of composure.

"Good morning!" I sing. "How are you today?" I hand her my health card pre-emptively. The receptionist looks up with a smile while her pencil scratches a checkmark on her list and steers us to the left.

This waiting room is furnished like a French Provincial sitting room, with walnut side tables and bergère chairs upholstered with toile fabrics. Muted sage camel-back tufted sofas grace like ballerinas with their gently rolled arms. Large paintings in ornate frames, accented with brass picture lights, hang on the walls. I melt into a cozy floral settee. Later, I learn about the local philanthropist who furnished the waiting room so patients could be at ease prior to surgery.

Soon, I'm ushered to another area. The team flows so seamlessly! They talk to me genuinely while efficiently working. I'm in awe of how I feel cared for. They're maintaining eye contact! My brain lowers its guard, and I melt into the gurney.

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#### Buzzzzzzzzz.

The sound reverberates from under the sky-blue drapes. I hold my breath as I imagine the surgical tools drilling through my crown. My head twinges from the cold clamp gripping my skull. Despite being tightly strapped onto the OR table, tension eases as I silently recite memorized verses from the Scripture, *Bismillahir-Rahmanir-Raheem* (In the name of God, the most Gracious, the most Merciful). I hear an unfamiliar voice on the other side of the drapes. I assume it's one of the fellows starting to give me instructions as they coached me prior to surgery. "Can you wiggle your toes?"

"Yes," I obediently reply. As I help them identify different areas of my brain, I have a growing urge to sweep over to the other side of the drapes, to be part of the OR squad. I wonder how my brain looks! Before my thoughts wander further, my hand jerks rhythmically. *Oh no! Help!!* 

Hours later, I awake to a familiar voice. "We'll stop here," my neurosurgeon announces. "I know she wants to continue to work as a physician." *He was actually listening to me during my consult!* We converse about my family and kids as he meticulously works.

Postop, my insolent body lies limp. Shimmy a bit to get comfortable. My eyes widen as commands to my left side fall on deaf ears. I can't move my left arm or leg. Words are not flowing out as quickly as I'm thinking them. "It's Supplementary Motor Area syndrome. We expected you'd experience this complication," one Fellow states during rounds. I nod politely while trying to recall the informed consent. I had assumed that the discussion was just a formality. As an MD, I'm used to providing informed consent and reassuring patients that complications are rare. My throat burns as my brain fiercely tries to say something.

"There is a rare, albeit temporary, sequelae from this type of surgery," I hazily recollect my surgeon saying weeks ago. "It spontaneously resolves within days. We used to think the brain had eloquent functioning, but we now know it has plasticity. Patients' brains figure it out, and functioning recovers spontaneously. If that occurs, your hospital stay might be longer." I sustained that rare complication. I won't be out of here quickly after all...

After several days, the team updates me that they clinched a bed at a neurorehabilitation hospital. It's Christmas time, and guilt swells in my helpless shell, feeling I'm burdening them during the holidays. *They* 

should be enjoying the festivities, not taking care of me. They swaddle me up in blankets like a mummy while two EMS chatter boisterously with the ward staff.

Between snippets of time with the rehab team, I stuff the rest of the void by immersing in sweet luxuries, like audiobooks. Or lazily critically appraise neuro-oncology guidelines and papers. *Well, at least I get to practice what I learned from grad work!* I convince myself. My care squad teaches me how to pace myself at home by attuning to my body, mind and emotions. *Emotions*. I have been trained to suppress these as a professional.

Weeks slip by. My husband is frustrated by the tiny bouts of rehab. "It's daily, though," I whine, biting my lip. I do enjoy their positive feedback on accomplishing simple tasks, like placing rings onto pegs.

"We need more intense rehab at home," he purses his lips. I'm in a rehab hospital—you can't get better care than that, right?! My brain screams. And I'm one of the lucky ones who got a spot so quickly and didn't have to wait. Especially during the holiday season! Then, I start noticing how time does sloth by. I turn my attention to coordinating my outpatient rehab. If I'm capable of making all these arrangements, I wonder, do I really need to be in the hospital?

Once home, my days are spent training longer with my newfound spirit. I'm elated as my recovery progresses earlier than expected. Practicing the tenets of my faith bolsters my mindset further: *never give up*. Determination shoots through my veins to not let anything push me down, not even my cancer. I soon get clearance to return to work and carefully dip my toes back in.

"It's so hard to climb stairs," a patient would share. A flight of stairs is still a challenge for me, too. "That sounds frustrating," I'd respond. "Tell me more about how this makes you feel." I infuse more moments to reflect on their story, closely examining how they share it, when they pause, how they'd shift uneasily in our grey plastic chair. Just like I once did when my ophthalmologist noted a sign that catapulted me to my diagnosis. Patients of 17 years begin opening up about their vulnerabilities. Why now?

Has my illness experience made me more attuned to their suffering? Or is it because now I inquire more about their emotions – something I yearned to be asked about during my journey? While I don't know for sure, what I can say with more certainty is that I no longer fear that my cancer hinders my ability to care. While healthcare workers were stretched thin, their compassion still touched me, leaving an indelible mark. Sensing authenticity, I lowered my guard and placed full trust in them. From my family physician listening to how my unexplained symptoms were impeding my quality of life, to my care team bearing witness to my suffering, I felt genuine care, that they were there for me. My extended family gave me space to open up and share my whole illness journey, which kindled my healing. It ignited me to re-evaluate my purpose in

life. Through spirituality, I rediscovered meaning and forged my path to heal. This revitalized lens now drives my purpose to heal with compassion, not only for my patients, but for myself, too. ■

### **Biographical Note**

Aisha Husain has been practicing comprehensive family medicine for nearly two decades in a rural community. She is an Assistant Professor at the University of Toronto. Her passions include medical education and faculty development in narrative-based medicine to cultivate well-being.