Speechless

Less than 2 percent of the world's population has red hair, and only around 2 percent have green eyes. When you do the math, approximately 0.04 percent of the population possesses both traits. Research even suggests that the genetic combination of red hair and green eyes is one of the rarest to be observed (Lin et al., 2016).

My mom coaches cheerleading at a local high school in Iowa, she likes her steaks cooked well done, she's always telling me I need a haircut, she's an incredible artist, she taught me to never arrive at a party empty-handed, she sits on the porch and holds the ugly old barn cats that nobody else pays attention to, she cuts bouquets of lilacs for the vase in the kitchen every spring when they bloom, she's the first person on the dancefloor at a wedding and she's not afraid to drag you out there with her, she can talk with anybody and often does, and she keeps framed photos of her 3 children in the center of her desk. My mom has red hair and green eyes.

I can't tell you how many times my mom has embarrassed me, but I guess that's what moms are supposed to do from time to time. You should've seen her at my wrestling competitions when I was in high school. I'm still uncertain if she actually understood the rules of the sport, but she was always there— yelling for me louder than the cheerleaders ever did. From the grandstands, she echoed wild encouragement while reenacting wrestling moves on my dad. In the midst of a serious physical competition, there's nothing more motivating than the booming voice of your own mother screaming, "buck him off, Jacko!"

My mom's birthday falls on December 27th, an unfortunate date for a birthday, always getting lumped right in with Christmas. Nobody ever knew what gifts to get my mom and I imagine it's been that way her whole life. On her birthday this year, my mom received her first

chemotherapy and radiation treatment. Weeks earlier, she was diagnosed with a high-grade astrocytoma. My mom has brain cancer, specifically an IDH wildtype, MGMT methylated glioblastoma which manifested in the form of a 5.3 x 3.6 cm cystic left frontal lobe tumor (larger than a golf ball) and an additional 1.5 cm tumor in her left thalamus.

Glioblastoma is an infamously aggressive, recurrent, and difficult cancer to treat. The first-year post-diagnosis survival stands at 40 percent, dropping to 17 percent in the second year, and a mere 6.8 percent by the fifth year (Thakkar et al., 2023). Phrased differently, the median survival rate is 14.6 months (Glioblastoma Research Organization, 2022). There is no cure for this disease.

Sometimes, many times, my mind gets the best of me, and I do the math. I calculate the odds that when I walk across the stage on graduation day, I'll hear my mom cheering for me, just like she used to do in that dim lit high school gym. I estimate the probability that she'll make me take way too many photos in my cap and gown, the likelihood that she'll see her sons and daughter get married, or the chance that she'll to get to hold her grandchildren.

"I remember seeing that on a PowerPoint slide somewhere. Didn't we learn about it in that one lecture?" This is a common phrase among medical students when prompted by an image, drug name, or disease they had encountered before but couldn't recall the fine details. It's something familiar, lingering on the tip of the tongue and the edge of our memory—still foreign—until suddenly, triggered by an unknown stimulus, our minds retrieve what we were looking for. Clarity dawns and we remember the significance once again.

When I spoke to my mom for the first time after returning home for Thanksgiving break, she was in her bathroom putting on makeup. I asked her how she's been, what the latest town drama was, and how she liked driving her new car. Her responses were limited to one-word answers, which was highly unusual given my mother's talkative reputation. Curious, I asked what she was getting dressed up for. She couldn't articulate a response, though it seemed like she wanted to. My mom was the first person I'd met with a production aphasia. Having only learned and read about the condition in class, it took me a moment to recognize its manifestation in the shakiness of a voice that didn't belong to my mother.

When I came to the realization, I attempted to refute every possibility that crept up the hierarchy of my differential diagnosis that populated in my mind noxiously and without invitation on the way to the hospital. I reassured myself, saying all the things I wanted to hear, cherry-picking the details of my mom's health history that refuted the worst-case scenarios. She's young, she exercises, she doesn't smoke, doesn't drink, and the list went on and on.

My mom undergoes radiation five days a week and takes chemotherapy pills every night before bed. She takes Temozolomide and is subjected to radiation which induces DNA damage and triggers apoptosis in cancer cells. She takes Bactrim to prevent pneumonia during treatment-induced immunosuppression, Zofran prior to chemotherapy to avoid vomiting up her medication, and receives biweekly intravenous bevacizumab infusions to inhibit new blood vessel formation in the growing tumor. Soon, she will be offered the option to wear an Optune cap which emits alternating electric fields to impair the division of cancer cells when applied to the shaved head of a patient for a minimum of 18 hours per day.

The occurrence of drug side effects is rooted in the complexity of the human body, making it challenging to develop drugs that exclusively target one part without affecting others. In the realm of chemotherapy, the distinction between friend and foe is blurry. The rain falls on the just and the unjust alike. Healthy cells die and cancer cells die more frequently. On her current treatment regimen, she is likely to develop short term memory loss and lose the ability to learn new tasks. Additionally, there is a heightened risk of spontaneous cerebral hemorrhage, bowel perforation, and radiation-induced brain necrosis.

When I was a kid, I remember listening to the song "Live Like you Were Dying" by Tim McGraw. My mom always got a kick out of that tune. However, she never found herself skydiving, rocky mountain climbing, or going 2.7 seconds on a bull named Fu Manchu. Instead, shortly following her diagnosis, she continued to volunteer just as she always had. She bought gifts for children on Christmas and remained a steadfast supporter of local child adoptions as a court-appointed special advocate.

Over the past few years, my mom has adopted the habit of taking a walk every morning to the local airport and back, greeting our neighbors with a wave as she passes by their front windows. Recently, I started joining her. One morning, on our way back down the driveway, my mom spoke. "I don't want to die," she said softly. I hugged her as the sunrise burned off the morning fog in the valley.

I've never seen my dad cry before. I reckon this is one of the few times in his life where his willpower, critical thinking, and physical strength couldn't solve a problem for our family. Shortly after my mom was diagnosed, a surgery was scheduled to remove the majority of the tumor from her brain, and a meeting was called to determine treatment options.

My family, unfamiliar with medicine and the healthcare system, turned to me for answers, relying on my "extensive" 1.5 years of medical school knowledge. They asked about genes, drugs to try, and which institution we could send her to. I applied the skills my medical training had taught me thus far, trying to contribute anything in my power to aid my mother and family as we navigated the unfamiliar path of a cancer diagnosis. I delved into research articles, sifted through clinical trials, reached out to doctors who'd given us lectures in the past, and joined support groups on social media. I searched everywhere for a silver bullet that didn't exist.

Over the past few days, we'd all taken turns staying overnight with my mom in the hospital. The night before her surgery, I lied awake in bed. Powerless would be the best way to describe the feeling in one word. It's an emotion that has continued to bleed into my mom's treatment process like a scab that keeps getting pulled off as new information and complications are unveiled.

Having undergone the removal of a kidney myself, I'd wrestled with this feeling before, but the kidney doesn't possess our conscious experience and existence amongst a complex and still undiscovered synaptic network. Our brains are more than just what we know; they are who we are, with every experience informing every decision we make. Everyone you ever knew, every food you've tasted, sight seen, song heard, and hand held.

Someone was going to remove a piece of my mom's brain in the morning. I lied there, hoping the surgeon was getting a good night's rest. I hoped they weren't lying awake like me.

In neurobiology, we are taught to view the brain as a prediction machine. Through evolution, the brain adapted, enabling organisms to better perceive and control aspects of the environment and their internal state. Our experiences—joy, pain, successes, and failures inform our behaviors and decisions, shaping our understanding of the world around us. It is this schema, in part, that prompts us to seek explanations when problems arise, aiming to understand what went wrong to prevent future occurrences. And so, we ask ourselves, "What mistake was made that led me to this experience of pain? Why did this happen? Who is responsible?"

As I stared across the hospital room at the fresh, pulsating incision on my mom's scalp, I found myself grappling with the cliché question that will never receive a sufficient answer: Where was God in all of this? How cruel and unusual to take away the voice of a woman who uses it to spread love and laughter?

I thought about how my mother used to seat us in the front row of church every Sunday. Back then, she told us that God could see us better in the first row, so we had to be on our best behavior (a veteran parenting move I now realize). Fearmongering aside, she instilled in us the principle that standing up for what you believe and loving the people around you was the best way to live.

In that moment, I couldn't help but wonder why God couldn't hold up His end of the deal?

My mom is the kind of person you can't get to stop talking—the definition of a social butterfly. There's a running joke in our family that she can't go to the grocery store and make it back out without seeing someone she knows. As a child, I was often dragged along to go shopping with my mom, and I never liked stopping to talk. I was the kid tugging on her pant leg, silently pleading for her to wrap up the conversation so we could get home.

Looking back now, I envy the ease with which my mother approached social interactions. She always knew everyone's names. Standing between the potatoes and onions in the produce aisle, she would ask parents about their children. She always knew which colleges they were headed off to, which sports they got recruited to play, and who they'd recently got engaged to. She made conversation effortlessly and made friends just as easily. If you didn't love my mother, it was because you hadn't met her yet.

Due to the tumor, my mom struggled to speak in the days leading up to her surgery. We held onto hope that her speech would return to normal after the tumor was removed, but it did not. Today, she comprehends everything we say to her. She listens to audiobooks before bed because she can't read like she used to. Despite maintaining her intelligence, expressing herself verbally is difficult. She cannot always convey what she wants when she wants to say it. Occasionally, she calls me by our dog's name, but I don't mind.

One night, my mom confided in me that she felt trapped inside her own body. She feels embarrassed when friends and neighbors visit or take her out to dinner, unable to inquire about their children or order her own dinner without help.

Even texting became a challenge because her messages no longer made sense. She stopped texting me while I've been away at school. Talking on the phone is difficult too, and I can sense the frustration in her voice when she tries to express how much she misses me but can't get the words out. In an attempt to bridge the gap, I preemptively answer questions I know she'd want the answers to. "And mom, before you ask, I just got a haircut."

For as long as I can remember, family tradition has always involved game nights, and we're a competitive bunch. I vividly remember my mom playfully taunting me with a trademarked John Cena "you can't see me" hand gesture during a recreational game of Go Fish. Recently, we decided to play Kings on the Corner. When it came time for her turn, it took my mom quite some time to lay down a card. On the next round, she missed an opportunity to move a king to the corner. We all laughed and told her it was no big deal. Since then, family game nights have taken a back seat, and we've unintentionally transitioned into a long-term game of charades—trying to decode what my mom is attempting to say.

This weekend, we attended the wedding of a close family friend. It marked the first time my mom had ventured out to a large social event since she had been diagnosed. As I listened to the bride and groom exchange their vows, the classic lines resonated with newfound significance: "For better, for worse, for richer, for poorer, in sickness and in health...till death do us part." Out of the corner of my eyes, I watched my dad squeeze my mother's hand in silent affirmation. That night, my mom danced to the Cha Cha Slide.

In my experience, old stories of mistakes and near misses are always funny, especially when retold with people who were there. Like the time I got suspended for doing doughnuts in the high school parking lot on a snow day or when the football coach surprised us with a team run on the hottest day of the year, and we all ended the day with vomit on the front of our jerseys. Pain and suffering become funny because they no longer hurt. I'm still waiting and hoping to laugh about all of this someday. "Remember when you couldn't talk, Mom? Remember when we thought you weren't going to make it?"

It's a sunny day in February, the kind that gives you hope for spring, the kind that makes locals remind you that we'll get more snow before it warms up for good. I'm sitting in a café with my mom. My dad drove her up to school to surprise me this weekend. Next week, she'll undergo her first MRI since starting her treatment to determine if the regimen is working or not. Yet, our thoughts and conversation are not consumed by the impending milestone. We're drinking lattes and laughing at the corgi with stubby legs hobbling down the sidewalk across the street. We're retelling the stories we've heard countless times and laughing at the punchlines like it's the first time we've heard them.

I have been the one in a clean white coat telling someone that their life will change forever, I have been the nervous patient waiting to be rolled back to the operating room, and I have been the person holding the hand of a sick person that I love.

If life and medicine have taught me anything, it is this: we wake up in the morning with the false impression that tomorrow is a guarantee and too often we take the people who populate our everyday lives for granted. Why is it only through tragedy that we are reminded how we should have been living all along? When tragedy strikes, we hug our parents and children a little longer. We tell people how much we love them; how much they mean to us.

I challenge you to live in spite of tragedy. Call your parents for no reason other than to tell them that you love them, tell the custodian good morning on the way to your office, wave at your neighbors when you walk by them in the street, catch up with your friends when you run into them at the grocery store, cheer for your friends and family like you're the only one in the crowd, pull the car over on the way home from work to cut lilacs for the vase in the kitchen, and never show up to a party empty-handed.

References

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