

Living with Hypoparathyroidism: A Journey of Pain, Perseverance, and Purpose

By: Reeti Ahluwalia

In July 2018, I was officially diagnosed with hypoparathyroidism—a rare and chronic condition that, until then, I had never even heard of. My journey to that diagnosis wasn't just marked by a name in a doctor's report. It was a long, painful, and emotionally draining path that began with a total thyroidectomy (TT) in April 2018, performed to remove papillary thyroid cancer. What I thought would be the end of one health battle unexpectedly opened the door to another—one that would affect every part of my life in ways I couldn't have imagined.

A Complication No One Warned Me About My surgery came with complications. A post-op hematoma developed, and it wasn't just painful—it drowned all my parathyroid glands. I remember doctors later referring to them as "stunted." In the beginning, I didn't understand what that meant. What I did understand was that my body wasn't functioning like it used to. I suffered through seven excruciating tetany attacks in just three weeks following the surgery. No one explained why my muscles would cramp so violently, why my hands would lock up, or why I felt so paralyzed by fear and confusion every time it happened. It felt like I had become a medical mystery to everyone around me—and yet, there was no mystery to me. Something was wrong. Very wrong. But no one could give me the language or the comfort to understand what my new normal was. Every two hours, I was poked to check calcium levels. My veins were bruised and exhausted, and I was given IV calcium once, sometimes twice a day for weeks. These moments were full of pain and vulnerability, but what hurt the most wasn't the physical part. I was told I would be home within days, back with my seven-month-old daughter and my two-year-old son. That I'd be back breastfeeding, back to being the mother they needed. But April came and went, and I never made it home. I missed bonding moments and milestones I'll never get back. My breastfeeding journey with my daughter came to an abrupt end, and that loss, though often minimized by others, gutted me in ways I never fully expressed.

Silent Struggles, Hidden Pain Eventually, I was discharged and went back to my life—except it didn't look anything like the life I knew. I was now a cancer fighter trying to understand what Hypopara meant while being a mother, wife, daughter, sister, cousin, niece, friend, and full-time digital marketing manager who depended on over 40 pills a day just to function. Most days I moved through life with a smile on my face, but inside I was struggling. I told no one about the emotional and mental toll hypopara was taking on me. I figured, if I didn't say it out loud, maybe it wasn't real. Maybe if I kept pretending, it would all just disappear. But it didn't. I became really good at showing up—at meetings, at family events, in conversations—but I was completely disconnected from myself. I was grieving the old me, and I didn't know how to talk about it. I feared people would see me as fragile or broken. So, I swallowed my fear and pain, much like the calcium pills I took day in and day out.

A Global Pause That Made the Noise Louder Then came COVID. The world hit pause—work paused, social lives paused, the hustle paused—but my emotional turmoil grew louder. There was no noise to drown it out anymore. I started spiraling. I had nightmares, anxiety attacks, and would wake up drenched in sweat. PTSD gripped me in ways I couldn't understand. I didn't recognize myself. I was falling apart and had no idea how to put myself back together. One night, as I lay tossing and turning, desperate for peace, I had a thought that would change everything: I can't be the only one going through this. There must be

more people like me—people battling this disease, physically and emotionally, and feeling utterly alone. And that’s when the Hypopara Warrior Instagram account was born

Finding a Tribe In April 2020, exactly two years after my diagnosis, I launched Hypopara Warrior—a small, humble corner of the internet dedicated to sharing my journey and reaching out to others walking the same path. I had no expectations. I simply wanted to be seen and to make others feel seen. What I didn’t anticipate was how quickly and deeply I would connect with others. Suddenly, I wasn’t alone. There were people out there who got it—who understood the language of tetany, the frustration of endless pills, the fear of not knowing what tomorrow would feel like. We spoke, we confided, we cried, and we celebrated every little victory. We laughed at the absurdity of being vitamin D junkies and mourned together during the setbacks. It was raw. It was real. It was healing. That space became my therapy, my journal, and my support group all rolled into one. It helped me rediscover purpose in my pain. For the first time in two years, I didn’t feel like a victim—I felt like a warrior.

A Glimpse of Light: TransCon Trial Amid this personal transformation, another incredible opportunity came my way. I was enrolled in the TransCon PTH trial in Canada. This clinical trial offered something I hadn’t dared to hope for—a chance to reduce my dependency on those 40+ pills a day and reclaim some quality of life. Slowly and under careful medical supervision, I began weaning off my medications. I documented every step of the journey on Hypopara Warrior. I shared the highs, the lows, the changes in my energy, mood, and sense of self. My goal was simple: to be transparent, to give hope, and to show that maybe, just maybe, there was a light at the end of this long and winding tunnel. This wasn’t just about me anymore. It was about all of us. Every story shared, every DM exchanged, every “me too” in the comments reinforced that what we were doing together mattered.

Looking Back, Moving Forward Now, several years since my diagnosis, I can finally say this: I am no longer at war with my body. I am no longer silent in my suffering. I have found strength in vulnerability, power in community, and purpose in my pain. Living with hypoparathyroidism is still hard. It’s a lifelong condition, and it doesn’t come with a cure or a blueprint. But I now know that it’s possible to build a life around it—one that includes joy, connection, growth, and even healing. I’ve learned to advocate for myself, to ask the hard questions, and to be gentle with the parts of me that are still grieving. More importantly, I’ve learned that sharing your story can be an act of survival—not just for you, but for someone else who’s out there feeling lost and unseen. To anyone reading this who’s just starting their journey with hypopara, I see you. I know it’s scary and confusing and exhausting. But I also know you are not alone. There’s a whole community of warriors out here, waiting to walk this path with you. You don’t have to do it in silence. You don’t have to do it alone. This is my story—but it’s also our story. And together, we’re rewriting what it means to live with hypoparathyroidism—not as victims, but as warriors.