

## Our Journey to Parenthood With Hyperemesis Gravidarum

The journey to parenthood is different for every person, filled with an endless array of circumstances and emotions ranging from worries and fears to plentiful hopes and dreams. For us, it was an idea that brought my husband and me joy even before we were married. Becoming a mother was always a desire for me. I easily imagined the romance of a typical pregnancy—the one you could generally follow along to in books like *What to Expect When You're Expecting* and the various pregnancy apps that gave you a peek at what you might expect during any given week. I eagerly awaited the experiences I saw many of my family and friends have during their pregnancies as they carried an ethereal glow and ability to delight in growing their peanut. But the story of creating our family has not looked like the one I had envisioned, the one dreams within your heart and soul are made of. Our story has had any sense of idealism overshadowed by a darkness that comes with anxiety, fear, and an unrelenting physical illness. It has included mental and emotional struggles and so, so many tears—outright moments of sobbing. Our story's chapters on starting parenthood and expanding our family have included the company of a rarer complication of pregnancy called Hyperemesis Gravidarum (HG).

In its most simplistic terms, HG affects just 2–3% of pregnant women. It is characterized by unrelenting nausea, vomiting, dehydration and varying weight loss exceeding 5% or more of one's pre-pregnancy weight. However, this just scratches the surface, as HG tends to open the door to a whole host of secondary complications (malnutrition, organ strain, dangerously low blood pressure and high/low blood sugars, etc.). Moreover, this does not even begin to dive into the deep spiral of one's mental health, and any HG sufferer will tell you that there is no adequate way to describe what it is like to *experience* HG. To understand all of the ways HG negatively touches nearly every aspect of your life, you would have to struggle with it yourself. Continuing to live each day while pregnant with HG, managing to do even the smallest of normal tasks while pregnant with HG, requires a strength most will never need to endure during their own pregnancies. I cannot stress enough that it is not a condition that is magically fixed with crackers, ginger of any kind, oils, sea-bands, acupuncture, or any combination of things you might think would help nausea and vomiting. Trust me when I say that an HG sufferer has tried all of the things that “should” help, and which can assist your average bout of morning sickness. Much different from even bad morning sickness, HG is in its own right a mini-chronic illness physically lasting anywhere from 5–9 months, but one that is widely understated and misunderstood, leading many HG sufferers to feel isolated and unheard by those closest to them. And while it is commonplace for someone who has never suffered from HG to read all of this and find themselves pondering whether any one of these statements is an exaggeration—that it surely cannot be as bad as superficially described here, or that the feeling of being alone and withdrawn is something self-imposed—rest assured that HG is medically classified as a debilitating complication of pregnancy that leads to many maternal and fetal consequences, including loss of life. Just one of the daunting statistics of an HG pregnancy is that *1 in 3* HG babies do not make it to term. I have this overwhelming urge to tell you that if there is anything you take away from reading this, it is that you understand that HG is so more than what you see and that what HG sufferers need from you is for you to listen.

My first pregnancy in 2015 brought a violent cycle of nausea and vomiting weeks before a pregnancy test would detect I was pregnant. My first trip to the local emergency room for IV fluid rehydration was at just three weeks. I would spend another two weeks frequenting the ER in this manner before finally testing positive. In fact, we were so early along that a misreading of an ultrasound taken during one of my ER visits resulted in a talk about following up with my OB/GYN because it looked like I might have an ovarian cyst (turns out, that was actually a very early embryo taking form). Weeks and weeks into feeling as if I had a combination of the worst flu and hangover imaginable, I took another pregnancy test in the midst of moving into our first home. Two faint lines appeared. I remember staring in disbelief at the test, and throwing all of my visions of how I would tell my husband the wonderful news out the window, solemnly relieved to finally have a reason for why I felt like utter garbage while also unable to shake off the feeling that something must be wrong for me to feel this sick—I had never been so ill in my life. Our joy in the news felt short-lived as we shared a fear about my current state. Days later, we sat in with one of the nurses at my OB/GYN clinic where I would first learn about HG and of my diagnosis. At this point, I still had no actual idea as to what having HG did and would mean for me. I began to watch spring and summer plans unravel. At just eight weeks I was restricted from flying—forcing me to cancel a multi-destination early summer trip to see friends and family—and put on a cocktail of medications to try to combat the nausea and vomiting. Even on chemo-grade dosages of anti-nausea medications and barely ingesting any actual food or drinks, I would throw up multiple times each day, often dry heaving until passing out from exhaustion, often sleeping on my bathroom floor. I continued my trips to the ER every few days to rehydrate. Desperate for some sense of normalcy, I pushed to continue to work my normal schedule as being at home huddled in a ball on the bathroom or bedroom floor mentally and emotionally felt so defeating. But it is inevitably where I ended up every single day. During this time, immediate family members and colleagues were told on a need-to-know basis. Barely feeling like I could keep my head above water in what felt like physical chaos within and around me, I watched control over sharing our news slip through my fingers, people most often finding out while I fielded questions about why I had withdrawn socially.

At 13 weeks I continued to rapidly lose weight and was ultimately admitted for two weeks for more direct medical intervention, eventually having a peripherally inserted central catheter (PICC) line placed. As a condition of my release, I would keep the PICC line in place and begin at-home care with a local pharmacy and infusion treatment center, receiving total parenteral nutrition (TPN) through my PICC line overnight for 12 hours each night. TPN is a way of supplying all of the nutritional needs of one's body by bypassing the digestive system and dripping a nutrient solution directly into a vein, and is used when a person cannot or should not receive nutrition or fluids by mouth. In my lighter moments, I have referred to it as my nightly dose of liquid cheeseburgers. I grew to have a strong love/hate relationship with my PICC lines (I would have two during my first pregnancy, one clotting and failing midway) and TPN routines. I will be forever grateful that they helped grow my first child when I could not, but TPN carries with it its own risks, daily stressors, and side effects—my personal experience included liver and kidney strain and gestational diabetes, the latter of which would cause our daughter to land in NICU shortly after her arrival for a week to combat low blood sugars.

I was ill for the duration of my entire first pregnancy, but had “fluffier” days between weeks 20–28 where I could stomach some breakfast and a light lunch and most light smells of food or cleaners around me. Even on these days, I was fully medicated, connected to my TPN, and vomiting each day. Around 28 weeks, HG resurged with a vengeance. *Nothing* seemed to work. Because I began to dehydrate again and began light contractions as a result while simultaneously having complications from the TPN, we moved to a more aggressive IV fluid rehydration at the local cancer infusion center. We began weekly fetal monitoring appointments and growth scans to monitor our little one, my amniotic fluid levels sinking at times and showing minimal movement by our daughter. After weeks and weeks of stressful monitoring, with just a couple days’ notice my doctor induced me at 38 weeks realizing that complications were only growing. The relief I felt to know that it was almost over was indescribable.

Our daughter arrived after a relatively short labor, and my symptoms of HG began to near-immediately subside. But quickly after we arrived to our recovery room, she was whisked away to NICU with no real notice as her blood sugars began to fall into a critical range. It began a sequence of feelings and events that seem to be seared in my mind. Though having only hours earlier delivered her, and against the advice of every single nurse, doctor and medical professional responsible for my recovery, I was promptly dressed and hobbling through the pain from my room to hers to be with her. She would be in NICU for a mere six days, but it felt like a lifetime at the time. Watching her tiny heels be pricked and squeezed for a measurable dose of blood repeatedly for sugar monitoring I could not help but feel responsible for each cry that escaped her lips. That *I had caused this*. That my body had *failed me* during my pregnancy, and as a result, *I had failed her*. I would hold these thoughts within my mind for weeks, never speaking them aloud until I found myself standing at our kitchen counter supplementing my milk supply with formula after another failed nursing attempt one evening. Though latching immediately after birth, because she had been moved to NICU and her blood sugars and intake were being strictly monitored, most of her feedings were through a bottle. It would take weeks for us to rekindle our nursing relationship, during which I would again feel pings of guilt. That evening, standing at the counter, I felt the sting of a hot pool of tears fill my eyes and stream down my cheeks. I retreated to our master bedroom and proceeded to cry uncontrollably for the next half hour, virtually inconsolable. Waves of the physical, mental and emotional stress and moments of guilt of the previous nine months that had been generally dammed into a corner of my mind came crashing over me. Looking back at this moment now still brings me to tears. It was so clearly a storm of feeling inadequate and helpless, and a lightening-bright sign of suffering from post-traumatic stress syndrome (PTSS), something I would not truly recognize for some time.

Discussions about mental health today continue to lean into the more taboo subjects we talk about with one another, including maternal mental health. In many countries, as many as 1 in 5 new mothers experience some type of perinatal mood and anxiety disorder, including postpartum depression. Often unnoticed and untreated, these illnesses frequently can have tragic and long-term consequences to both the mother and child. What’s more—from the mom with the perfect Instagram, to the mom with the 15-month old showing up for playdates and BBQs with a smile on her face, to the mom who always seems to have it “together”—*no one* is immune. For mothers

who suffer through HG, the risks are greater she will suffer from depression, anxiety and/or PTSS. In fact, according to the HER Foundation, 18% of HG sufferers will suffer from PTSS.

After the arrival of our first, the idea of expanding our family to the three or four children we had dreamed of seemed no longer bearable. Before I had even delivered our daughter, my doctor began bracing me for the dim facts surrounding HG in subsequent pregnancies, warning that there was an 84% chance HG would repeat, and that symptoms were statistically slated to be worse with each subsequent pregnancy. For a solid two years I could not even begin to fathom being pregnant again, still to this day suffering from flashbacks to my first pregnancy. Each time I find myself brushing my teeth and tongue, happening to trigger a quick gag-reflex, I think of how often trying to brush my teeth while pregnant would cause me to vomit. Any time I would feel an unease in my stomach from something I ate or just being under the weather, I feel the anxiety of the mere idea of vomiting wash over me. I cannot count the number of times I was casually asked by people who “*knew*” I was so violently ill in my first pregnancy—and that I was expected to face the same challenges in the next—when we would have our second, and the fiery internal reaction I would have to that question. As Daenerys would say, ‘Dracarys!’ But rounding into our daughter nearing age three, my husband and I began to talk about trying again. Only these conversations were not your typical ‘let’s expand our family’ conversations. They were very much focused on the logistical questions—*Was I ready? Could I do this again? What happens if...?* For me, the decision to become pregnant again was a battle of a mother’s desire to have another child put square up against knowing in advance the physical, emotional and mental demands that sit ahead and *choosing* to accept them this time. A battle of my heart versus my mind. In an act of logical defiance, we began trying with me telling myself that it was now or never, that if I waited any longer I would not be able to talk myself into this choice again. Sitting here six months along, I still question whether I made the right decision for myself and our family as the negative impacts of HG this pregnancy sit scattered about.

Incredibly withdrawn during my first pregnancy in a 9-month battle as we ourselves struggled to understand what was happening, only small pieces of our family and a minimal amount of friends were made aware of the struggles we survived. Escalating this, though I pride myself on being helpful and supportive to others, I am quite terrible at asking for help—though at the time I had no idea of what help could possibly look like in a situation where I could not seem to help myself. All I knew was that I often felt alone and that no one seemed to understand, and most did not seem to try understanding. It seemed that I barely heard from a variety friends and family and felt overwhelmingly unsupported by many I had managed to confide in. One of my closest friendships would be permanently damaged, the pain of their lack of presence in a time of great need and subsequent reactions to my sharing that hurt taking months for me to process. My perspective on many relationships I held close to me would inevitably shift. I knew that should HG be part of this second pregnancy, being an advocate for my needs from those around me and having a solid support network would be imperative for my mental and emotional well-being and, in contrast to the physical symptoms of HG, assumed that this piece *had* to be easier in a second round. But it has been unexpectedly harder in some ways.

HG wriggled its way into our lives again in mid-December 2018 and I was formally re-diagnosed as having HG the day after Christmas and reclassified as being high-risk. This time, my medical team was effectively standing guard and ready to fight with me from the beginning, with an array of prescriptions filled and a standing order for IV rehydration commencing. By mid-January, I was admitted to the cancer infusion center 2–3 times each week for IV fluids, with bi-weekly appointments with my doctor. I could not stomach *anything*, vomiting every day, including in bags while driving home from work. After losing 5% of my pre-pregnancy weight in a matter of weeks, I was admitted for a PICC line again at 13 weeks and began daily at-home care with the local infusion pharmacy to receive daily overnight TPN therapy. The mild relief I had between weeks 20–28 with our first would not show for this pregnancy, dialing down in severity only for a few short weeks to allow me to at least ingest something for breakfast and lunch, though throwing it up by evening.

As statistically predicted, the physical symptoms of this pregnancy have been worse, full of far more triggers that seem downright unfair. For nearly the first five months, I could not stand to take more than a lukewarm shower, needing to sit for most of it as the sound and feel of the water touching my skin would cause me to vomit. I slept in a makeshift bed on the floor because something about its hard coolness would soothe me to sleep, only recently reverting back to our bed simply because the weight of the growing little one has become a bit much for my weary body. My rock star of a husband now sleeps on the floor in my place because his radiating body heat flowing across our bed would make me vomit. I have slept next to a waste bin every single evening since December because I *hate* being hovered over a toilet vomiting. My three year old has grown accustomed to my missing family dinners, and to creative, cold dinners—sometimes venturing into a quick microwavable option to get things started—for currently 141 days straight. I have had to have conversations with her to ease her mind about my being unwell, and that though she has seen me vomiting more times than I care to acknowledge, explaining that growing a baby makes her mommy not feel well, but that all will be okay. I miss zoo and museum dates, play and dinner dates, and am bed-bound 80% of the time I am home. My husband has grown accustomed to, among other things, minimal conversations actually spoken especially in the evening hours as talking aloud has been a trigger for me, and carrying much of the weight of parenting and household needs these past six months. I quite literally do not know how I would be able to manage this pregnancy without his unwavering support, the moments where he does not take it personal my avoiding the warmth of his touch or kiss for fear that it will for even a millisecond make me feel more nauseous, and his scouring the stores and Amazon to find *something* that sounds good for me to drink for that particular week before I grow tired of feeling sick after drinking it. He has endured everything from crazed pregnancy hormones and unrealistic demands to the darker moments with HG where I simply sit in tears after vomiting again. I cannot imagine his journey and how helpless I know he has conveyed he has felt at times, but more I cannot imagine making it through this without him.

During this second pregnancy, so far I have had:

*20 outpatient hospital visits; 4 at-home nurse visits;  
1 PICC placement; 14 PICC dressing changes;  
48 liters IV fluids; 90 TPN bags;  
3 episodes vomiting while driving (literally no use counting the rest of  
the episodes because you just lose track);  
5 ultrasounds; 1 blood clot;  
3 medical insurance appeals for medication;  
3,384 mg Zofran; 2,820 mg Diclegis*

Despite all of this, there has admittedly been a certain dreary ease in this pregnancy as I have had a better understanding of some of the physical challenges to expect on the path to our second child. Still, there is no way to prepare entirely for the many days I have felt like my body is simply trying to quit on me. There have been so many moments of feeling as if I cannot possibly get out of bed and go through another day of battling for something I want, but which feels like my body tells me I should not have. I did not anticipate the amount of guilt I would need to address as I watch the burden this pregnancy places on my husband and daughter—the challenges they have been forced to face as we try to work together to make it to the end. I cannot describe the level of exhaustion I feel at the end of every day when I wipe the makeup from my face that tried to hide some of the outward symptoms of my illness and after having spent the day offering half-smiles or replies to each person who casually asked or said any of the following:



This brings me to the piece of having an HG pregnancy that is more delicate in nature because it involves virtually every person around you, from colleague to friend to family, and the impact each of those individuals can have on an HG sufferer's mental and emotional state.

Most every HG sufferer has heard the comments and questions I mention, yet nearly all HG sufferers wish otherwise. Though each tends to be said or asked by a well-intentioned person, unknowingly the reality is that they are received as insensitive and each fails to transmit any form of real empathy to someone who is suffering from HG. In the same breath, HG sufferers also *get it* and have been there, too. Unfortunately, as a society we tend to be of the mindset that feelings of sadness, anger and grief are seen as problems and we instinctively try to “fix” things or find

solutions. But this is misguided as with many illnesses, there is no way to fix an illness of HG's magnitude. There is no way to fix the loss of one's self in every sense of the word an HG sufferer can feel during their pregnancy. There is no way to solve the sadness that comes with telling your existing child(ren) that mommy needs to be in bed and cannot go play outside. There is no way to put a Band-Aid on the anger and hurt that an HG sufferer feels when she feels unheard and unbelievably as she is suffering each day. And so while these good intentions are geared towards repairing a situation, it leads to an HG sufferer feeling even more isolated.

I have blogged about this a bit on my side pregnancy blog on Instagram (my "Instablog") and began trying to tackle not only things not to say or do when you have a colleague, friend, or loved one suffering from HG, but have primarily focused on things you *can* alternatively say or do to be helpful. Surprisingly, it is really quite simple, but seemingly harder for people to absorb and act on because, again, we as a society are too focused on immediate fixes.

Quite literally, the first thing you must do is to *believe* an HG sufferer's words. If you cannot set aside your disbelief in how harrowing this condition is (it is hard for a *sufferer* to even believe at times), you will never be able to provide support. On my best days and seemingly about average, I consider my HG to be in the middle-ground of severity when I am fully-medicated. I have personally found that because I have, by the grace of God, managed to have minimal impact to my work schedule—most definitely having the brunt of the impact hitting my home life as I literally exert every ounce of my energy to keep our family's finances stable for the coming maternity leave—I am repeatedly faced with a perception that things must not be as bad as I say they are because, *who could possibly work through it*. Not easily is the candid answer. But I saved for over a year to be able to financially afford to be off with ease for the entire duration of my unpaid maternity leave, while still being able to save for inevitable purchases coming like a car that could accommodate our growing family and the monstrosity that is increased daycare costs. I could easily be at home, and probably would fare better with my exhaustion levels if I were working an at-least reduced schedule. However, I am refusing with everything I have to allow HG to steal my hard work from me, and so I show up to work most every single day, pushing through every minute I feel nauseous and want to vomit. I find myself practicing deep breathing techniques frequently to keep that lump in my throat that signals I should probably get to a waste bin at bay. I have limited my in-person meetings, rarely leave my office, and am relieved when it is finally time to return home knowing I've managed to accomplish something that felt impossible today by being able to make it through a full day. That has been every single workday for the past six months.

Once you believe, the most supportive thing you can do for an HG sufferer is to be willing to be present and to listen. On its face, it seems so simple, but this is the part that I have found to be excruciatingly absent during each of my pregnancies. As I have connected with other HG sufferers and survivors across the world, it turns out this is something nearly non-existent in many of their experiences.

In both pregnancies, I have been hurt by and angry with *so many* people because of this. For good portions of both, I have felt many friends seemingly vanish. That because friends and family members cannot understand, they say or do nothing at all. I carry scars of how alone I felt during my first pregnancy, of friendships I stepped away from because the hurt was too great. As I headed

into my second pregnancy, a similar lack of support arrived despite being more vocal about ways to help me feel supported. There are friends and family I barely hear from. Others have been defensive and accusatory when I carefully tried to explain how some things led me to feel alone and hurt, while others simply say nothing at all. I can count on one hand the amount of friends and family who have been present in my pregnancy, some of those being individuals I had harder heart-to-hearts with and us coming out on the other side, and will be forever grateful for feeling heard by each of them. For those I have not felt present, knowing the damage that feeling angry and hurt can cause when I am already struggling to feel grounded, I have been better about compartmentalizing many of my feelings and instead keeping relationships where I am not finding support at a distance until I am able to make it through my pregnancy. Still, the question begging to be asked—if you have a good, supportive group of friends and family around you, *how can this be?*

As easy as it is for people to be present, it seems it is equally as easy for people to retreat when someone they love is going through something awful and unfair. I, myself, have done it plenty of times. It really comes back to a need and desire to solve problems and a societal struggle to show real empathy. No one wants to see their loved one physically ill for one moment, let alone nine months of those moments. It is hard to know what to say when you see a loved one suffering, knowing there is nothing you can do to fix or take away their pain. We try to relate instead of really hearing the sufferer so we have an opportunity to learn how they are feeling. We scurry to find some inspirational bit to share or optimism to hang in their sky instead of standing next to the person while they are in the trenches and storm. We tend to mistake a need to be present as a need to be physically present. Though there are times when the latter is needed, it is amazing how *present* one can be by simply reaching out or acknowledging just how awful things are.

For an HG sufferer, the scale of good and bad days is skewed from the norm, and the bad days are plentiful. HG is not a simple complication that quickly goes away. It is nightmarish months and months of feeling awful while trying to somehow manage growing a life within. It feels and *is* horrendous. HG makes you question not only things around you, but also your own self. You feel like a failure because your body is fighting against one of the most wonderfully natural things in life. Most every decision you make every waking moment is dictated by a consideration of the impact it will have on your existent condition, and how much more sick it might make you. You grieve the loss of the pregnancy ideals you had envisioned, having those dreams replaced by a literal need to try to survive every single day. HG forces conversations about one's ability to make it through an existing pregnancy, let alone any future pregnancies. This list could go on and on, but is all to say that there is great opportunity for you to reach out to an HG sufferer and to simply ask, "How are you *today?*" To acknowledge that you are remembering they are suffering and realize their life feels to be—and physically is—in a state of distress, and to ask if there is something you may be able to do to help, and not to set the responsibility of asking for help at their feet.

Nevertheless, more than remembering or acknowledging, being willing to hear the responses and to provide support *in the way the sufferer has conveyed works best for them*. I stressed the last part because I have admittedly been fortunate enough to have a number of individuals in my life

who at the onset of my re-diagnosis of HG this second pregnancy have offered to do things for me. And while I appreciated their generous offers, they were not things I needed or could take advantage of at the time and so I kindly thanked them and instead suggested that the greatest support for me right now is to simply feel a sense of presence by *hearing* from them, yet have been met with a deafening silence from many. I am here to tell you firsthand—and secondhand from fellow HG mamas—that these small tweaks in approaching someone who is suffering from HG may seem insignificant, but in reality, they make a world of difference. Remember, an HG sufferer does not need someone to swoop in to make everything better, because that is impossible. We need support allowing us to feel anchored on solid ground so we can wake up each day ready to fight again. All this said, there are those who are simply not in a position to be able to offer support, *and that can be okay*. At the same time, those individuals may also have to respect that an HG sufferer might have to keep the relationship at a distance to protect themselves during the very hard journey that is HG.

For our family, there is a heartbreakingly sad realization on the horizon knowing that this is the last time I can currently fathom choosing to physically battle in an effort grow our footprint. While that is just one of the many conversations that HG has forced, it is one simply sitting at the back of our focal point as we still have three more months of battling for this second little love. Amidst all of the feelings of inadequacy and failure that HG showers upon me, God reminds me each time I lift these feelings and my fears to Him, praying instead for grace, that I am stronger than I know even when I arguably feel to my core otherwise. In our story, the narrative is not what we had in mind, but I trust that He has a plan and we have unwritten chapters ahead to live that are bound to be filled with love. For now, we take things one moment at a time and count the victory of surviving another day in the HG storm.

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If you or someone you know is suffering from Hyperemesis Gravidarum, you can find some helpful resources through these sites:

HER Foundation (<http://www.helper.org/>)

Pregnancy Sickness Support (<https://www.pregnacysicknesssupport.org.uk/>)