

None of My Mom Friends Are Dying

Category: Stories

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I'm squarely in the middle of my friends, in terms of when we became "mom friends." However, one aspect sets me apart: None of my mom friends are dying.

None had excruciating pain during pregnancy, unrelenting constipation or unexplained blood in their stool. None went septic five days postpartum or were ultimately diagnosed with stage IV colon cancer with liver, lung and peritoneal metastases. None are parenting a two-year-old, knowing that they might not see him turn three.

It's not surprising that I'm unique among my friends in this way. Colorectal cancer (CRC) during pregnancy is rare, occurring in one woman per 50,000. Applying this ratio to the 3,664,292 US births in 2021, I'm one of seventy-three extremely unlucky women. Such cases often involve delayed diagnoses, because CRC symptoms often present when the disease is relatively advanced, and are masked by pregnancy symptoms. Looking back at my pain-filled pregnancy, the clues were there—but no one deciphered them until too late.

I was so excited to become pregnant, determined to stay physically active and continue my usual busy routine as an environmental scientist, hiker and quilter. Unfortunately, my actual experience was very different. By mid-second trimester, I was enduring left-sided abdominal cramping that made even a thirty-minute walk challenging. I was also extremely constipated and had

blood in my stool, but my obstetrician explained these as common pregnancy symptoms.

At thirty-two weeks and six days, the cramping suddenly became a sharp, agonizing pain, folding me in half. The next morning, at my thirty-three-week appointment, my obstetrician recommended more stool softeners and told me stories about other patients who'd experienced pain during pregnancy. I remember feeling baffled, and guilty about complaining.

Is this awful pain truly typical third-trimester discomfort? I wondered. Do I just need to be tougher?

That night, the pain became so horrific that I couldn't stand up. My husband took me to the emergency room. I was checked for premature labor, had normal ultrasounds of my ovaries and left kidney, received fluids and two unhelpful morphine doses and was sent home. With my pain still undiagnosed and untreated, I felt stuck. This *had* to be wrong, my pregnancy had to be different—but the clinicians I encountered didn't seem concerned; they were just focused on my baby's health and apologetic that "pregnancy hurts."

I had unmanageable, mind-numbing, stabbing pain for my remaining five weeks of pregnancy. Hot baths or numbing my midsection with ice packs provided brief reprieves. The pain often made me curl up on the floor and cry, barely able to think or communicate. I thought about suicide often, wanting to cut my left side out of my body, torn between loving the tiny creature growing in me and wanting to tear him out and scream at him to stop, *please stop kicking me*. Feeling yet more guilt over those feelings, I hid them from even my closest friends—reminding myself, *Don't complain too much, because everyone hurts during pregnancy*. I kept eating healthy, drinking fluids, taking stool softeners and limping to my OB appointments.

Somehow, somehow, I made it to induction at thirty-eight weeks and two days. After delivery, I had less pain, but still enough to impact everything: walking, nursing, chores, sleeping. I'd heard that the postpartum period is hard, so again I thought, *I just need to be tougher*.

Five days after our son was born, my husband rushed me to the ER. In thirty minutes, I had gone from feeling chilly to shaking so hard that I couldn't nurse my baby, to being septic, with a 104° fever. I was terrified, certain that I would die. After being stabilized, I spent nine days in the hospital. The hospital was wholly unprepared for an inpatient who was a new mother but not technically "postpartum." After repeated arguments, I was finally allowed to have my husband and six-day-old baby stay with me.

I told my hospital providers (obstetricians, hospitalists, infectious-disease doctors, etc.) that I still had left-sided abdominal pain and blood in my stool. This elicited little concern, even as my sepsis remained unexplained. My care team seemed not to think beyond obstetric-related causes as they examined an otherwise healthy-looking young woman with a baby latched to her breast and a swollen belly.

On my sixth day there, an infectious-disease nurse practitioner finally found

a hard lump in my left abdomen, leading to a diagnosis of a “tubo-ovarian” abscess. A month later, a follow-up CT confirmed a previously discounted connection between the abscess and my colon.

I was admitted to the hospital for a next-day colonoscopy, which revealed a racquetball-sized tumor that had perforated my colon. I now believe that the perforation happened when I was thirty-three weeks pregnant. In retrospect, knowing that colon perforations typically require emergency surgery, I’m horrified and furious when I recall having gone to the ER, only to be sent away—my concerns dismissed, I believe, because I was pregnant.

During this hospital stay, I lost the argument to have my family stay with me. I sobbed as my husband left with our baby—our first separation, hours after my cancer diagnosis. A nurse mentioned that the “few spots” on my liver and the “nodules” on my lungs made the diagnosis more serious, without further explanation. Two days later, when we met with an oncologist, I understood why. I remember sitting next to my husband as he rocked our baby’s car seat, hearing the words “stage IV” and “two-year life expectancy” and shaking my head in utter disbelief.

One week later, we moved across the country to be closer to my parents. The following week, I had colon surgery.

My cancer diagnosis confirmed that my misgivings about my pregnancy had been well founded. Even while berating myself for not being tougher, I was enduring more than should be expected of any woman. Also, my diagnosis meant there would be much more hardship to endure, and many more ways that motherhood would differ from what I’d envisioned. Within the space of six weeks, I gained two drastically different new identities: first-time mom and incurable cancer patient. These roles elicit emotions that run the gamut, from love and joy to sadness, anger and anxiety.

Reflecting on my experiences as a patient, first as a pregnant woman and then as a cancer patient, I mostly feel a deep sense of betrayal and loss. My body betrayed me by letting the cancer take hold and hide behind my pregnancy. My healthcare providers betrayed me by implying that my symptoms and pain were not unusual and by allowing my pregnancy to limit and distort their clinical assessments. I lost my ability to breastfeed for as long as I’d wanted—an aspect of motherhood that I found deeply important and meaningful. I will never regain the physical strength and independence that I should have as a thirty-two-year-old. With ongoing chemotherapy, I continue to lose hours and days I would otherwise spend with my son.

Most importantly, I will ultimately lose the ability to raise my son with my husband—to watch him grow, to support him as he becomes his own person. There is no greater loss.

I’ll never know if an earlier diagnosis would have been possible or could have saved my life. I hope that sharing my story will encourage other women to trust their instincts about their health, and remind medical providers of the risks of anchoring and confirmation biases as they deliver patient care.

Above all, I hope that my story will help even one woman to be no different from all of her mom friends.