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The Unexpected

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The first real punch in the gut.

The first sense that I might not be well came hard and fast and knocked me to my knees. There had been other diagnoses, but nothing that I had given much thought to. But this one, this diagnosis, left me sitting on the bathroom floor, curled up into the corner by the bathtub. My hands cradled my head, elbows on my thighs, crying so hard that breathing seemed to momentarily stop. My heart broken beyond what I thought could ever be repaired. Thinking that the life I wanted would never be granted to me. Grieving for what wouldn't be, couldn't be. I'd experienced major surgeries, broken bones, and took them in stride, just a part of life. But this was not supposed to be a part of my life.

Two hours before this, I sat with my husband, Bill, in front of the reproductive endocrinologist's desk, an appointment we'd waited three months to get into, in hopes of discussing ways to increase my chances of conceiving. We sat nervously in her office. Our normally loquacious conversations fell

to silence. I sat fidgeting in my chair, picking at my fingernails. He sat studying the many brochures that he had grabbed from the waiting room.

My OB/GYN, Dr. B, had scheduled this appointment for us. We had been trying to get pregnant for almost two years and had been seriously trying for the past six months. The last months were a series of calculating my monthly cycles, buying ovulation kits from the pharmacy, and making our sex life more of a scheduled activity rather than a romantic act between husband and wife. We both wanted children, and I was now 34, Bill, 40. Each month seemed to bring more and more stress, as each month I was not getting pregnant. My periods even seemed to respond by becoming irregular.

When I explained to Dr. B that we had been unsuccessful at conceiving, she recommended that since I was almost 35 (apparently a marker for conception and reproductive concerns), I should come in to see her before my annual checkup. I went expecting to have a full pelvic examination, including a Pap smear. Instead, she examined me quickly, stating that my uterus looked fine and sent me to the lab to have my blood drawn. She told me that she'd call me with the results. When she did call I was sitting at my desk at work. Usually one of the nurses called to follow up with any issues, or to discuss examination or lab results. This time it was Dr. B herself.

“Do you still want to get pregnant?” she asked.

“Yes, of course!” I responded, a bit confused by the question.

“I want you to see a reproductive endocrinologist. Your blood results have me a little concerned. I set up an appointment up for you with Dr. T, a reproductive endocrinologist I’ve worked with in the past. You don’t have to keep the appointment, but I recommend that you do. I want you to get in as soon as possible. The soonest she can see you is three months from now.” She explained that I had a general release form on file with her office, and asked me to call my primary care physician (PCP) to ensure that I had a form on file with her, too. She wanted my PCP to send all of my current medical records over to Dr. T.

I stood up from my desk, closed my office door, and asked anxiously, “Is there something wrong with me?”

She told me that my FSH, or follicle stimulating hormone, was high.

“How high?” I asked.

“High,” she replied.

“What does that mean? How high is it?” I inquired.

She expressed that she didn’t want to put too much emphasis on the number before I had more lab work. FSH is a hormone that helps control a woman’s monthly cycles and stimulates the ovaries to release eggs. “Sometimes the numbers can be off. I want you to have it retested. Come in to the lab, preferably two to three days after starting your period. Are you still getting your period?”

Yes, I was still getting my period. Why would I not be getting my period? She gave me the address and information for the doctor and told me that we’d follow up after the appointment.

I knew people who had sought out the assistance of a reproductive endocrinologist. I knew this was the doctor who specialized in helping women get pregnant, usually by means of a variety of fertility treatments. I'd prefer to conceive naturally, but wouldn't be opposed to fertility treatments if necessary. Later that evening, when Bill and I discussed the conversation between me and Dr. B, neither of us felt too concerned. We thought that, at worst, we would discuss fertility options at the appointment, but we didn't think they would be necessary.

We continued trying to conceive, both of us hoping it would happen naturally. We did not succeed. When we drove to the appointment, we were still full of hope, curiosity, and willingness to do whatever we needed to get me pregnant.

The reproductive endocrinologist's office was relatively plain, except for the pictures of Dr. T's two beautiful children that seemed to cover almost every available surface: pictures of babies with adorable little bows attached to barely enough hair to hold them in place, laughing siblings sitting side by side in matching outfits, babies playing, babies smiling. Cruel, almost—this excessive display of happy, beautiful children. Why would a doctor specializing in fertility treatments have so many pictures of babies, and why would they all be pointed at the chairs in front of her desk, rather than inward, towards her?

Dr. T walked abruptly into the room, not making immediate eye contact. She was carrying the medical records from my OB/GYN and my PCP.

When she was halfway through the room, almost to her desk, she aloofly introduced herself. Then, not even completely seated, and without any hesitation, she blurted out, “It would be virtually impossible for you to get pregnant using your own eggs.”

I sat and stared at her, not quite registering what she had just so casually and curtly said. Surely she was going to follow up with a more reassuring statement. She did not. Confusion started setting in. My husband’s hand found its way to mine. He held it gently. I was shocked. Bill was defiant. “You can’t possibly sit here and say that it would be virtually impossible for her to get pregnant. You haven’t even examined her yet,” he said in the authoritative, terse voice he reserves for people who really piss him off. “Besides,” he continued accusingly, “I noticed here in your brochure that you specialize in donor egg pregnancies.”

“No, Mr. Wasserman, I have not yet examined her, but I do have the lab results, and your wife has gone through an autoimmune form of premature ovarian failure, a type of premature menopause.”

Failure? Menopause? I had no idea what she was talking about, and why ovaries and menopause and failure were being used in the same sentence. She went on to explain that, due to antibodies shown in my lab results, it seemed my body was attacking my ovaries as if they were foreign objects. “We will need to discuss other matters after the exam,” she continued. “I will need to examine you, before I have the nurse take your

blood samples. So, Ms. Wasserman, if you would, please meet me across the hall in the examination room. Get undressed and put the gown on.”

I was still speechless. My husband asked, “Why can she not use her own eggs? And how can you say she’s gone through menopause? She still gets her period.”

Dr. T explained that (according to this particular lab’s results) the FSH of a woman who is still menstruating would be between 4.7 and 21.5. A woman who has gone through menopause would have an FSH of 25.8 or higher. My FSH was 89 from the first lab result, 98 from the second. “When was your last period?” she asked.

“Six weeks ago,” I answered quietly.

“And the period before that?” she continued.

“Five weeks prior,” I said.

“Well, you should stop getting your period any month now,” she stated, as she stood and began to walk out. “Please meet me in the examination room.”

I was confused. What was she saying? Did she just say I can’t get pregnant? Did she say I’d gone through menopause? Ovarian failure? Was I hearing her correctly? I’m too young, I’m only 34! I felt myself losing control over my tightly held emotions.

I stood up and stumbled enough that my husband had to steady me. As we left the office, I excused myself and slipped into the restroom. I stood, trembling, looking up at the ceiling (as if that’s where my God resided) and pleaded, “No. No. No. Anything but this. Please, no. Don’t take this away from me.” Tears started coming. I lost

my legs for a moment and had to crouch on the floor. I tried to compose myself, and wiped the tears. More came. I wiped them again. Tears continued to stream down my face. I stood and took several deep breaths. There was no way I was letting that woman see me cry. I had to look as if I had not just been shattered into millions of pieces. I took a paper towel and wiped my face.

I entered the examination room wearily, surprised to see only my husband present. The room was quite large and resembled an operating room. In the middle of the room was the examination table, surrounded by many pieces of medical equipment that I was unfamiliar with. My husband immediately stood and walked over to me. "Are you okay?" he asked softly, as he rubbed his hands on my upper arms and shoulders. I just stared at him, trembling, feeling only loosely attached to reality.

"I need help," I said in a voice so faint, I could barely tell it was mine. "I need help" is not a phrase that ever passed through my lips. At those words, Bill more fully understood my state of mind.

He began helping me undress. We stood almost stomach to stomach, as he slowly took off my clothes, making sure one arm was somehow always around my quivering body. I could not tell if I was cold from the temperature in the room, or from shock. Bill sat through the examination holding my hand. I was receiving a transvaginal ultrasound; the doctor was trying to get a closer look at my ovaries. At one point, I wondered if she realized that I was an actual human, with both physi-

cal and emotional feelings, and not a cadaver that she could just shove an instrument inside of. After the examination, I sat staring into Bill's eyes as a nurse drew 12 vials of blood from my arm. "You're doing great!" he encouraged me. I could tell he was as upset by this completely unexpected experience as I was.

We sat through the doctor's post-examination meeting, which was mostly a blur (either from the shock of the experience, or from the enormous amount of blood that was just taken from my arm). I remember discussions of the need for hormone replacement therapies, bone density tests, genetic labs in California. She mentioned that my recent diagnosis of hashimoto thyroiditis, and adult onset asthma, along with my self-reported increase in joint pain were of concern to her. She wanted to look for other autoimmune diseases and inflammatory markers. I remember mentions of adoption as an option, the use of a surrogate, possibilities of donor eggs. Mostly though, I remember hating her.

My husband drove us home. We sat mostly in silence, except for our description of the doctor—who we will forever refer to as "The Devil Doctor." At home, I slipped once more into a bathroom (which for some reason seemed a safe place to hide).

This is where Bill found me. "Joy. Joy? Joy!" I could not answer. I could barely breathe through the sobs. I was too distraught at the idea that I could not bear children. As a little girl, when I was asked, "What do you want to be when you grow up?" I had always answered, "A mommy!" I could

not fathom that this might not happen; that being infertile was something that would be part of my reality. Somehow, sitting on that bathroom floor, almost in a fetal position, seemed fitting.

When Bill opened the door, he took a moment to notice me. “Oh, Joy, come here.” When I didn’t move, he sat his 6’1” frame next to me on the floor, wrapping his arms tightly around me. “Breathe, Joy, breathe. Shhhh. Just breathe.” We sat this way for a very long time. He held me close, and rocked me back and forth. I could do nothing but sit there, still weeping heavily. How many tears could possibly come? My usual strong self was too distraught to even stand. My mind was flooded with thoughts of *premature menopause*, *autoimmune issues*, *ovarian failure—failure, failure, failure!*

“I’m sorry,” I managed to squeak out, suddenly full of feelings of guilt and inadequacy.

“Oh, no. No! It’s okay. Everything is okay. We’ll figure this out. She’s only one doctor.” He grabbed me under my legs and around my waist and carried me to the couch. He held me, pulling the throw blanket over us both, giving reassurances that everything would indeed work out as it is supposed to.



This was the first biggie. The first big punch in the gut. One of many diagnoses of autoimmune maladies that would eventually lead to the diagnosis of systemic lupus erythematosus (SLE). Lupus SLE

is a chronic inflammatory autoimmune disease in which the body's immune system mistakes its own healthy tissue for an outside invader (such as germs, viruses, and bacteria) and creates antibodies to attack its own self. It can affect any part of the body: the joints, the skin, the organs, the nervous system, anything, any part of the body. Lupus SLE typically affects women during their reproductive years. Although the disease strikes mostly females, ten percent of those afflicted are males. There is no cure, and there is no known cause for the onset of this devastating illness. Lupus is known as the great imitator, often imitating other maladies within the body. Bill and I would soon find out how many illnesses lupus SLE could, and would, manifest.

At that particular moment, we did not know that we would sit many times on that couch discussing illnesses; sometimes full of sadness, sometimes full of fear. It now seems ironic that my husband whispered to me, "We'll go see another doctor." We had no idea how many more doctors we would be seeing; how many more vials of blood, how many CT scans, MRIs, procedures, X-rays, and tests there would be, following this first heartbreaking diagnosis. Premature ovarian failure was just the beginning of an unexpected journey that would take us along a very complex medical path, a journey we would walk through together.

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