

Flying Into Jerusalem

By Katherine Macfarlane

Sometimes, when I'm absentmindedly thinking of how many months are left in the school year, what might have been hits me hard. I was supposed to be pregnant by now.

The first time someone asked me when I was going to have a baby, I was on my honeymoon. Three and a half years later, the interest in my womb persists.

We still don't have kids. There are lots of reasons why we've waited. I wasn't ready. It was the wrong time. I felt like I'd just left childhood behind myself.

The questions about "when" really bugged me, and I had to get some indignation out of my system. So I started writing on my Facebook wall in the voice of a character I called "the Empty Uterus." After Thanksgiving, the Empty Uterus posted:

"Nope, just ate a really big piece of turkey and am still loading up on leftovers. Bloated, but not pregnant."

The Empty Uterus feigned surprise when presented with common knowledge:

"You're kidding. It's harder to have kids after you turn 35? But my 35th birthday is less than 9 months away!"

"Still empty," was my favorite Empty Uterus aside.

What no one knew was that in the midst of all this joking, there was a plan underway for getting a baby into that empty uterus. But because I have Rheumatoid Arthritis ("RA"), like all of my major life choices, this plan had multiple steps and contingency plans.

First, I had to test run how my body would react to going off some of the medication I was taking labeled "Category X," which is not safe for a fetus. One such medication is methotrexate. I'd been on it for about 15 years. Not only is methotrexate Category X, but at high dosages, it's used to induce abortion.

"Six months is safest to make sure methotrexate is out of your system," one doctor told me.

"Three months is fine!" said doctor two.

I chose the six-month approach. January, the month of resolutions, was my first methotrexate-free month. At first I felt no different. Then, around February, I flared, struggled to walk, and had to use a cane for a few weeks. But otherwise the methotrexate elimination went well. I didn't miss it.

At the same time I was going off methotrexate, I was getting pressured to stop taking Plaquenil, another powerful medicine known as a "disease modifier." My ophthalmologist was concerned that I'd taken it for so long that the accumulation of Plaquenil in my system could trigger Plaquenil-induced blindness. Because I have Iritis and Glaucoma in addition to RA, there's no good reason to risk making my eyes any worse. My rheumatologist resisted, wanting to keep me on Plaquenil, so the compromise was to half my dosage.

Then the weather got warmer, and I started spending more time outdoors. I noticed strange brown splotches on my forehead and nose, as though my skin was tanning but only in random spots. The one thing I've had going for me since adolescence is relatively good skin. All of a sudden I looked like I'd faked-and-baked too long at a Myrtle Beach strip mall.

"This is what we call "The Mask of Pregnancy,"" the dermatologist told me.

"WHAT?"

"No, you're not pregnant," the doctor said, chuckling.

"What you have is similar to the skin markings we see on women who are pregnant. Yours is from Plaquenil. It's making you photosensitive."

So no more Plaquenil.

By June, six months into my getting-ready-to-try phase, I was off Plaquenil and methotrexate, but still on Remicade, a chemotherapeutic agent infused every 8 weeks through an IV, in addition to the potent steroid prednisone. I was swimming and writing. The pain was manageable. I was feeling good, for once.

"I can do this," I thought.

Then I crashed. On top of the usual (swollen knees, perma-bent left elbow), my hips were aching. I couldn't climb stairs—I was pulling myself up them. I was lethargic and exhausted. I went on a Medrol pack, which pumps high doses of steroids into my system, and it worked for about a week. The day after the pills ran out, my knees swelled again. I packed on about ten pounds, which meant that once school started in August, most of my clothes didn't fit.

This was my pregnancy dry run. It was not going well.

Ever since I brought up the subject fifteen years ago, my doctors have given me vague assurances that pregnancy would never be a problem. That RA would not rob me of this experience. Year after year, no doctor could think of any reason why I shouldn't or couldn't conceive. But here I was in a downward spiral and I wasn't even pregnant yet. No one told me about this part.

The thing is, conception is one thing, and that's all my doctors were focused on. Maybe that's what they thought I cared about. But pregnancy, for me, is about much more than fertility. It may mean losing my ability to walk due to medication changes—I might flare before, during, and if I choose to breastfeed and continue to stay off certain medications, after, a baby's arrival. Independent of the medication changes, I could have pregnancy-induced flares.

"You'll go into remission," one doctor told me, painting an idyllic picture of what pregnancy would be like.

Some women with autoimmune diseases do experience a lessening of symptoms during pregnancy. Most autoimmune disease drugs are designed to suppress the patient's autoimmune system. Pregnancy itself suppresses the body's natural immune response to a baby's presence, so the experience of being pregnant may, as a side effect, mimic the drugs I take anyway. But the chances of that happening are, at best, one in three. And even if I experienced that 9-month reprieve, it still wouldn't resolve the pre- and post-pregnancy medication changes I'd have to make.

Still, all of this information wasn't going to stop me! The doctors said I could do it! On I marched in my pregnancy quest.

In July, I requested a bone density scan to see how much worse my hips had gotten in the past 18 months. It revealed that my right hip was now in the throes of osteoporosis, and that my left hip was on its way to the same fate. I've been on prednisone for 24 years, so in some ways, this is no surprise, but it's never easy to hear that you have the bones of an eighty-year-old.

Someone needed to put all of this information together. I made an appointment with a high risk OB/GYN because my rheumatologist and regular gynecologist had nothing more to add. They remained of the opinion that pregnancy would be "no problem."

My meeting with the high risk doctor was somber from the start.

First things first. Without methotrexate, I was flaring, and Remicade and prednisone, which I was still on and would likely stay on during pregnancy, weren't doing much to help. This was not a good sign—my body was telling me that it needed the very medication that I would have to stay off while pregnant.

And what about the medication not labeled "Category X"? The data on Remicade and pregnancy is sketchy. There is information about women who have taken it during their first

trimesters, and it appears that their babies all turned out fine. There is scant information on women who take it any longer, which suggests to me that anyone who has taken Remicade took it only before they knew they were pregnant, and then stopped. So what if I did stay on Remicade?

“The Remicade might suppress the baby’s immune system,” the doctor said.

Next we talked bone density.

“Have you broken any bones in unexpected situations?”

Well, yes. At 19, I broke a bone in my left leg while catching a rebound during an easygoing game of pickup basketball that pitted me against two girls who both hovered around 5 feet tall. One of them was wearing her shower flip-flops. This was not high-risk behavior, but it still resulted in a bone break, and it took me six months to recover, much longer than expected.

At 29, a jumping jack ended with a quiet crack—a stress fracture right above my left ankle, that healed, sort of, but still aches when it rains.

I am now prednisone-dependent, my bone density will only worsen with time. The stress on my hips could trigger a fracture during the pregnancy. Or after. Or maybe even during birth.

Even ignoring all of the above, there was still the unavoidable fact that my pregnancy would be high risk. Something else would go wrong—a third trimester miscarriage or even a stillbirth.

“So, this is what I need to know,” I told the doctor, who had neatly-parted white hair and seemed willing to give me concrete information.

“What do you recommend?”

He sighed. “You want me to tell you if you should try to get pregnant?”

“Yes,” I nodded.

“I can’t. That all depends on your tolerance for risk. You have to make up your own mind. Some women will do anything to have a baby. None of this would stop them. But most women haven’t been through what you have.”

I nodded some more.

“Let me put it this way, would you fly into Jerusalem tomorrow?”

The week we visited this doctor, the news was filled with stories of air strikes. Most flights in and out of Israeli airports were grounded.

“Well, no, of course not,” I said.

“There you have it,” the doctor concluded. He wanted me to think about surrogacy.

“Well, I don’t think I want to pass on my crap genes to anyone else,” I told him. “Adoption’s fine,” I said.

“I have three adopted daughters,” the doctor confessed. “We had fertility issues.”

I held it together until I reached the elevator bank, and only then did I let myself cry. Big salty tears dripped down my flushed cheeks. For the next few weeks, I’d think I was ok, and then I’d wake up in the middle of the night, remember what I’d learned, and cry some more. I felt like I’d let my husband down—we’d gotten married for many reasons, including that we wanted to have children together. His genes are worth passing on.

But for now, we’re not going to risk it. In the last five years I’ve endured two glaucoma surgeries, two ER visits, a pinched nerve, countless knee aspirations and injections, and never ending physical therapy. Each of these medical events was supposed to be simple but ended up with unpredictable complications and prolonged recovery. Even without a baby, I’m an unhealthy mess. I’m not ready to embark on another disaster.

We’re looking into adoption. And fighting desperately to get me out of this flare. The flare that I walked right into, like an idiot, to see what my body’s reaction to getting ready for pregnancy would look like.

I cry less these days. But I do have the lingering memory of a dream in which I saw a young girl, about five years old. She’s standing in a field, trying to decide if she should walk through an open wooden gate, the kind with a metal latch that swings open. The grass is high, and reaches the bottom of her knee-length dress. Her hair is blonde and cut into a chin-skimming bob—just like mine was at that age. In my dream she smiles when she sees me. She’s my daughter. I know her. I know her name, too. Jane.

I try to push self-pitying moments like this one away. I haven’t lost anyone I’ve held in my arms or carried in my belly. But I lost something. Maybe it’s just the promise of that dream, which I mourn in my own way—quietly, as I muffle my nighttime sobs. I mourn the one I’ll never know.

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