

MEMOIR



FROM TOP LEFT
Jessica's grandmother, Harriette, was a film actress in the late 1950s; Stephanie nursing Jessica when she was just one week old; Jessica's parents: Fred and Stephanie Queller.

Hard decision? Deciding to cut off your breasts when you don't have cancer and possibly never will? To me, that was insanity ... But waiting for cancer to strike didn't sound reasonable either.

"What do doctors recommend to women in my position?" I asked him.

"Well ... unfortunately, doctors can't yet offer any definitive guidance. The BRCA test has only been in existence for about nine years. It's a case of science outpacing our ability to know what to do with the data."

"You're telling me you don't know how to advise me?"

Danielle and I gazed at him in disbelief. If doctors were at a loss on this subject, how could a patient be expected to make the best decision?

Once I allowed the possibility of a mastectomy to enter my consciousness, life as I knew it ended. I stumbled around in a fog, brooding over my existential dilemma: "To cut my breasts off, or not to cut my breasts off, that is the question ..."

In the shower, in the writers' room at work, in the car, in

the yoga class, in bed in the dark at 3am – I obsessed over the potential repercussions of removing my breasts. It did not take long to conclude that my personal life would be in the most peril. If I had a mastectomy and reconstruction, would men no longer find me desirable? Would I feel deformed? Would I no longer feel like a whole woman? I'd griped about our breast-obsessed culture, but privately enjoyed the admiration men expressed for my own breasts. In retrospect, I found my

whining hypocritical. How would I feel now, if they were gone and replaced by plastic implants and tattooed-on nipples?

One sleepless night, I paced around my apartment, calculating time. I was now 35 and up against the biological clock. If I elected surgery at 36, I figured it would take me about a year to recover – physically and emotionally. That meant I'd be 37 when it was over. By the time I found a new boyfriend and established a relationship solid enough to get pregnant, I'd be – what, 38; 39? And once pregnant, postmastectomy, I'd never be able to breastfeed. I'd always looked forward to enjoying that symbiosis with my baby. Not being able to would be a great loss.

This train of thought sent me into a tailspin. Why had I sought out this genetic information? Yes, my mother had been blindsided by cancer, but at least she'd been able to live her life according to her own values and inclinations before it struck. Was a mutant gene going to rob me not only of my breasts, but defeat my ideals about love?

Or maybe this circumstance was the universe teaching me that my notions about finding a soul mate had *always* been impractical, that in order to have a family, more compromise was involved than I'd been willing to accept. I yearned to have children. *Bear* my own children. It was not something I was willing to forgo if I had any say in the matter. As unthinkable as a mastectomy was, I'd come around to considering it. I would never, ever consider having a prophylactic oophorectomy [the removal of ovaries] before I had children. That sacrifice was too great. Luckily, 40 was generally deemed a prudent age for BRCA-positive women to have their ovaries removed, which gave me five years. If I'd tested positive for the mutation in my 20s, doctors would have recommended I have children early in life and remove my ovaries sooner ... I'd long missed that boat.

After conducting extensive research and meeting with many doctors as well as other women who had opted for a prophylactic mastectomy, Jessica decided she would do the same on 12 September, 2005. Meanwhile, her sister and only sibling, Danielle, steadfastly refused to take the BRCA test. →

What is the breast cancer gene?

There are actually two – **BRCA1** and **BRCA2**. Their purpose, when functioning normally, is to prevent cancer by producing a protein that stops cells from growing out of control. In their normal state, these genes are tumour suppressors. However, when they contain mutations they cannot

control irregular cell growth and are the two main genes that increase a woman's chance of developing breast and ovarian cancers. It is now possible to test whether a person has inherited a mutation in their breast cancer genes. Diagnostic testing is available through family cancer clinics in most states.

For more information, contact the National Breast Cancer Foundation on 1800 000 118 or visit nbcf.org.au. You can also contact kConFab (the Kathleen Cunningham Foundation Consortium for Research into Familial Breast Cancer) on 1800 221 894 or visit kconfab.org. – *Kate Spies*

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The day before the surgery, I went to my plastic surgeon's office to have my breasts photographed using new 3-D imaging technology. This digital scanner would enable Dr Choi to determine the volume and contour of the breasts. She had explained to me that these measurements were most useful in the case of a single mastectomy, when they were trying to recreate a second breast to match the first. However, she was now taking 3-D scans of all her patients to have detailed before-and-after records.

I took my shirt off and a young woman drew Magic Marker markings on my breasts. She told me she was going to take photographs from all different angles. As she drew on me, I asked, "Don't you think this is odd?"

"What's odd?"

"That my breasts are here. We're drawing on them, photographing them. And tomorrow they'll be gone."

She looked up at me as a young woman, a peer, rather than as a medical practitioner.

"It is odd. I can't imagine." Her eyes flickered with compassion. "I'm sorry."

Two weeks after the surgery, I went in to see my mastectomy surgeon for an exam. He held the pathology report in his hand.

"You had precancerous changes in your right breast tissue, Jessica. Atypical ductal hyperplasia."

I was shocked.

"If you had any doubt about the course of action you chose, this should dispel it. You did the right thing."

It took five months and three surgeries (the final to create new nipples using skin from the hips) for Jessica's mastectomy and reconstruction – from a 10D to a 10B, which she'd always wanted. In July 2006, Jessica became an aunt; two months after the birth, Danielle took the BRCA test and discovered she too was positive. In March 2007, Danielle also underwent a prophylactic mastectomy; Jessica supported her sister through the ordeal.

Hollywood with heart

Six months before my mother died, we went to Los Angeles and visited Calista Flockhart – one of my best friends from my days working in the theatre. We scheduled a time to visit with Calista, who lived with her son Liam and boyfriend, Harrison Ford. We had been hanging out for an hour when Harrison walked into the den and joined us. He knew my mother was ill and sat down beside her – giving her his full attention. My mother transformed into a blushing ingénue before our eyes. As my mother described the room she'd built in her house solely for the purpose of hosing down her dogs, she giggled and tilted her head demurely. When it was time to leave, Harrison escorted my mother to the car and held the door open for her like a proper suitor. I will never forget what a gentleman he was. For the rest of the day and night, my mother forgot her stomach pain and mouth sores – that day, she was a princess.



FROM TOP LEFT
Jessica (left) and her sister Danielle both had the breast cancer gene; Stephanie died without ever knowing about the test; Stephanie with her mother Harriette.

I am now 37, with the perilous threat of breast cancer behind me and the threat of ovarian cancer still looming. I will have my ovaries prophylactically removed at 40. I am ready to have a baby.

The questions I'd asked myself – could I no longer afford to be true to my beliefs about love? Would I have to marry the next man who'd have me, in order to bear children? – I've since answered. No, I will not choose a partner out of fear of a biological clock. I've made bold choices throughout my life so that my external circumstances would reflect my internal convictions. I inherited a gene that statistically ensured I would get cancer, and I took action to prevent it. Love hasn't worked out according to my timetable, but I will have a baby and wait for love to unfold as it may. And so I'm heading to the sperm bank.

As I've already learned, the advances of biotechnology offer an array of choices, but they also come with ethical dilemmas. I've decided to be artificially inseminated, but I can take it a step further. A technique called preimplantation genetic diagnosis would enable me to test embryos for the BRCA mutation. I could then implant the embryos that do not carry the mutation.

I believe in utilising biotechnology to promote health. Of course I don't want my children to inherit the breast cancer gene, but there is no method to alter the genetics of an embryo. The only option is to select the embryos that don't carry the gene. Had this technology been available in 1969, I'd have ended up in the trash. Can I choose embryos that don't have the mutation and destroy the others? Is taking action to ensure my child will not go through the terrors my mother, sister and I have suffered the responsible choice? Or is it immoral to extinguish a life because it carries a gene that I live with? I'm about to dive into these uncharted waters.

Edited extract from Pretty is What Changes: Impossible Choices, the Breast Cancer Gene, and How I Defied My Destiny, by Jessica Queller (\$29.95, Vintage Books). m

