



The Other Jewish Women's Cancer

by ELIZABETH MICHAELSON MONAGHAN

OVARIAN CANCER DIAGNOSES LIKE MY MOM'S TEND TO BE DELAYED FOR SEVERAL REASONS. SYMPTOMS MAY BE IGNORED OR ATTRIBUTED TO OTHER COMMON CONDITIONS. AND NOT EVERYONE HAS WARNING SIGNS.

In September 2017, I get a call from my mother. "I have some bad news," she begins.

I think, Dad had a stroke. He has Alzheimers. Mom has Alzheimers. (This is my worst nightmare). "I have ovarian cancer," she says.

I know enough to understand that this is very bad news. Ovarian cancer is the deadliest gynecological cancer, affecting more than 22,500 women in the U.S. this year alone, and killing close to 14,000. It is caused by the proliferation of cancerous cells inside, on, or near the ovaries, the female reproductive organs on either side of the uterus.

My mother is 77. She walks 10,000 steps at her local nature reserve every morning. She doesn't drink, smoke, or eat junk food, and she loves salmon. She recently replaced spin class with yoga, and is proud of the fact that her doctor told her she has the bones of a woman half her age. My mother is a formidable bridge player, an excellent driver, and she reads two or three books a week. Her worst habit is binge-watching cable television shows in which people shop for wedding dresses and houses.

She was the first person in her immediate family to go to college, a psychotherapist, and later, the director of the non-profit outpatient mental health clinic she worked at for 40 years. As a parent, she is unsentimental to a fault, but she's a doting grandmother. She is the most competent and even-tempered person I know—the grownup I aspire to be, only with fewer Eileen Fisher separates. She is also loyal, having maintained the same haircut since 1975, and the same husband since 1968.

We have no family history of ovarian cancer, though my mother's sister (a former smoker) is a breast cancer survivor.

My mother explains to me that the stomach problems she's been having for the past few weeks are actually symptoms of ovarian cancer, and that she'll be having debulking surgery to remove the tumors, as well as her ovaries, fallopian tubes, and uterus in two weeks. My mother doesn't cry when she tells me this.

I struggle to mirror her stoicism. When I call my sister and tell her that mom has declined my offer to fly to Florida for the surgery, she is quiet for a minute. "I think we should go," she says.

SURGERY

The morning of the surgery I accompany my parents to the hospital. After my mom is wheeled away, my father and I sit in the waiting room and periodically check the electronic board that updates us on patients' progress. My mother is in pre-op for a long time, and in the operating room for even longer. At last her surgeon appears.

When he says, "Unfortunately, the cancer has spread farther than we thought," I realize his slumped shoulders and sympathetic expression are deliberate;

COURTESY OF THE ARTIST AND FRANÇOIS GHEBALY GALLERY, LOS ANGELES

he's been warning us of bad news since he walked through the door.

"Can you give us a preliminary staging?" I don't think he will answer.

"Stage IIIC," he sighs.

"Oh, Christ," I whisper, not very Jewishly.

This is why ovarian cancer is so dangerous, with a five-year survival rate of just 47 percent: the vast majority of cases are diagnosed after the cancer has begun to spread—and it spreads quickly, according to Susan Domchek, MD. She is the executive director of the Basser Center for BRCA and the Basser Professor in Oncology at University of Pennsylvania's Abramson Cancer Center.

Diagnoses tend to be delayed for several reasons. First of all, symptoms—like bloating, abdominal pain, loss of appetite, back pain, fatigue, and constipation—may be ignored, or attributed to other, more common conditions.

And not everyone has any warning signs: Amy Marcus Hollub, 55, a real estate professional in Miami, had "no symptoms at all," when she was diagnosed with ovarian cancer in 2009. "That's the scariest part."

In addition, while commonly used screening tools—ultrasounds, blood tests, and MRIs—can help identify some cancers before they're advanced, "There is no good way to detect early stage ovarian cancer," Dr. Domchek notes. By the time a pelvic ultrasound identified a mass on Hollub's ovary (which couldn't be confirmed as malignant until surgery), she had Stage IIIC ovarian cancer.

GENE TESTING

After the surgery, my mother is tested for cancer-causing mutations (changes) in 28 different genes. Mutations in the genes known as BRCA1 and BRCA2 account for much of the inherited risk of ovarian and breast cancer. They're

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found in 1 in 40 Ashkenazi Jews, compared to about 1 in 300 in the general population. Among Sephardic populations, the prevalence of BRCA mutations is likely higher than in the general population, but lower than it is among the Ashkenazim, according to board-certified and licensed genetic counselor Peggy Cottrell. Cottrell works at Sharsheret, a non-profit organization primarily serving Jewish women at increased risk of breast or ovarian cancer.

While ovarian cancer affects just 1.3 percent of all women, 44 percent of BRCA1 and 17 percent of BRCA2 mutation carriers will develop the disease by age 80. In fact, 29–41 percent of ovarian cancers in Ashkenazi women are thought to be the result of BRCA mutations.

"All ovarian cancer patients should be tested for BRCA1 and BRCA2 mutations," Dr. Domchek says. (Most BRCA mutation carriers in this country have not been identified, according to Cottrell.) Dr. Domchek explains, "BRCA1 and 2 are the most important as there are specific therapies which will be given based on a positive result." After her diagnosis, Hollub discovered she has a BRCA1 mutation.

Because several genes are associated with an increased risk of cancer in Ashkenazi Jewish women, when Cottrell does recommend genetic testing, she generally advises a multigene panel. Dr. Domchek includes the genes BRIP, RAD51C, RAD51D, Lynch syndrome genes, PALB2, ATM, and BARD as candidates for analyses.

THE PRICE OF PREVENTION

For BRCA1 or BRCA2 mutation carriers, prophylactic salpingo-oophorectomy (preventative removal of the ovaries and fallopian tubes) is recommended, as this can lower the risk of ovarian cancer by 80–90 percent. Dr. Domchek advises mutation carriers to have this surgery by age 40 (BRCA1) or 45 (BRCA2). Some BRCA mutation-positive women have their uteruses removed too, since the mutations may raise the risk of a rare, aggressive uterine cancer.

While the surgery has obvious benefits, it's not without drawbacks: The procedure induces menopause, raises the risk of osteoporosis and heart disease, and may boost patients' odds of developing dementia. It's not clear just how many BRCA mutation carriers have their ovaries and fallopian tubes removed, but in Dr. Domchek's experience, "most individuals do this by age 50."

Janet Levinson, 49, had her ovaries and fallopian tubes removed in 2014, and a double mastectomy in 2017. She discovered she had a BRCA1 mutation after her sister was diagnosed with ovarian cancer in 2013. While the decision to have surgery was "almost a no brainer" for Levinson, in part because autoimmune issues meant she wouldn't be able to have chemo if she did develop cancer, she wishes she'd known about



fertility-preserving options like egg- and embryo-freezing prior to having her ovaries removed.

Levinson confesses, “I feel like I cheated what life might have had in store for me,” namely, cancer. In addition, “I have felt guilty that I was in and out of the hospital so much, taking up the doctors’ time, getting surgeries—I never had cancer!” But, “When you have time bombs in your body, what are you going to do?”

If my mother is positive for any of the gene mutations she’s been tested for, my sister and I should get tested. However, if my sister or I are positive, while we can’t be denied medical coverage, we could be refused, or charged more for, disability, long-term care, and/or life insurance policies.

Moreover, “Even if you have genetic testing without using your medical insurance, you need to tell the truth on your policy application if they ask,” Cottrell warns. “Lying on your application may risk the loss of your policy.” For this reason, “It may be a good idea to get your insurance in place before you have genetic testing done.”

Still, “genetic testing may provide you and your family members with the information you need to save lives. Don’t allow fear of insurance discrimination to prevent you from getting the medical care you need.”

RESULTS

As it turns out, my mother doesn’t have any inherited gene mutations, at least none of the ones the tests checked for. I am strangely disappointed: If she doesn’t have an inherited gene mutation, then what caused my mother’s cancer? We are creatures of narrative, and explanations help us accept, or at least understand, the strange and implausible facts of our lives. But between the lack of hereditary risk and my mother’s aggressively healthy lifestyle, it seems that her cancer is one of the “66 percent of cancer mutations result[ing] from [DNA] copying errors,” or random bad luck, according to researchers at Johns Hopkins University. I find this infuriating.

And just because my mother doesn’t have these mutations doesn’t mean my sister and I don’t—our Ashkenazi father could be a carrier. Both men and women can inherit and pass on BRCA mutations, and if one parent has a mutation, there’s a 50 percent chance of a child inheriting it.

Unfortunately, not everyone knows that either parent can pass on a higher risk of breast and ovarian cancer. In Hollub’s case, two different obstetrician-gynecologists were confident that her grandmother’s and aunt’s early deaths from ovarian cancer shouldn’t concern her, since the affected relatives were on her father’s side. Hollub didn’t learn she had a BRCA1 mutation until after her diagnosis.

Regardless, “A negative result [for a BRCA mutation] doesn’t mean you’re in the clear,” Dr. Domchek warns. “If you have a family history, you still need

surveillance,” and should maintain a healthy lifestyle.

Great, I think.

CHEMOTHERAPY

In December 2017 my mom has the first of six scheduled chemotherapy sessions. For Stage III ovarian cancer patients with tumors no larger than 1 cm. after surgery, chemo delivered directly to the abdomen (intraperitoneal chemotherapy) may lead to better results. My mother’s oncologist doesn’t recommend this treatment. Is that because he “doesn’t think there’s evidence that it’s effective in patients over 65,” as he tells her, or because she still has some tumors larger than 1 cm., or both? Either way, my mother refuses to get a second opinion. As my father regularly informs me, her oncologist is a graduate of Columbia University’s Vagelos College of Physicians and Surgeons, and, I gather, infallible.

Hollub, who was advised to have (and received) both IV and peritoneal chemo after having her uterus, ovaries, and fallopian tubes removed, is glad she got a second opinion before starting treatment. (She eventually had two rounds of chemo and a prophylactic double mastectomy.) “It gave me more confidence in my decision. I wish women would appreciate that it’s OK to ask questions, and get second opinions. ... If you can’t be your own advocate, get someone to be an advocate for you, even if your doctor is the best!”

ASSESSMENT AND FURTHER TREATMENT

In Spring 2018, my mother finishes her six-session chemo cycle, and is evaluated for evidence of disease. “We’re going to beat this,” my father announces. Statistics offer (limited) support for his declaration: Remission is common after the first round of chemo, though in most cases disease eventually recurs.

Janet Levinson’s sister, Ruth Ann, 53, has had two recurrences of ovarian cancer since her original diagnosis of Stage IIC ovarian cancer in August 2013. During each bout, she’s undergone surgery and chemo. She’s currently on an oral drug, Lynparza (olaparib), which is what’s known as a PARP inhibitor. After chemo, PARP inhibitors can slow or halt disease progression in some ovarian cancer patients, including BRCA mutation carriers. As a person with recurrent ovarian cancer, Ornstein says, “I know my journey will never be over.”

But my mother is not in remission. Although some of her tumors have shrunk, she needs further treatment. Unfortunately, she has developed anemia, with too-low levels of hemoglobin in her red blood cells. This is a common side effect of cancer treatment, but in my mother’s case, the anemia is so severe that she can’t tolerate more chemo. Eventually, after several months of iron pills, inconclusive tests,

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and unplanned hospital visits, my mother has a bowel resection and comes home with a permanent souvenir, a colostomy bag.

A NEW APPROACH

At the end of the summer, the oncologist puts my mother on the PARP inhibitor olaparib. He lowers the dose several times, until her hemoglobin levels stabilize.

Over the next few months, my mother struggles to get, and keep, her hemoglobin levels up. Despite multiple blood transfusions, sometimes she can't take the olaparib. She uses a wheeled walker to get around, and sleeps more and more. Her oncologist suspects microscopic blood loss, but even a nuclear medicine GI bleeding scan in early 2019 can't find the source. During this scan, my parents learn that the cancer has reached her stomach. "But the oncologist doesn't seem concerned," my dad reports. "He said, 'We already knew that.'"

I am horrified. "I get the feeling that mom doesn't want to know any details about the cancer," I say, carefully. I am wild to know what's happening, as if by having more information I will be able to prevent the worst, or at least prepare for it.

"Me neither," my dad says cheerfully.

THE END

One evening in early April 2019, my mother calls me. "Do you know what hospice care is?" she asks.

"No," I lie, desperately hoping I am wrong.

"Well, it's when you stop treatment," she says. She sounds resigned. "The cancer keeps spreading, and the doctor doesn't think there's any point in continuing."

I am furious with the Ivy League oncologist. Why hasn't he been able to help her more?

She'll stay at home, my mother tells me. A local hospice will provide medical equipment, morphine, and eventually, round-the-clock nursing care. The doctor has given her six months. *October*.

My mother's decline is fast, then faster. When we visit her in April, she is still getting out of the house. By June, she needs help getting up from the recliner, and by July, she's had two falls and is stuck in an adjustable hospital bed. Permanently. When she calls my dad for help, her voice is weak and almost despairing. I've never heard her sound like this before.

I hate to see her world shrunk to the bedroom, the bedpan, the meals my dad has learned to make after 51 years of marriage. Her only real pleasure is watching cooking videos on her iPad. She is unflappable as ever, but when a visiting nurse asks her the year and the name of the town she lives in, she gets both answers wrong.

When I kiss her goodbye and tell her we'll all be down in September at the end of my August visit, I don't know if it's true.

My mother died at the end of August.

I catch myself thinking of her in the present tense all the time: I have to remind her about an upcoming series based on a book she liked. I will tell her what my four-year-old said. I wonder what she thinks about Elizabeth Warren's chances. I will hear her voice in my head for the rest of my life, I hope.

My mother would have said she was lucky. She was in good health for most of her life, and her life was quite long. She had excellent health care, and never had to worry about going broke in order to benefit from treatments or services. She was rarely in pain, and when she was, she received quick relief. She had a devoted family and caring friends, and all the comforts contemporary American life can provide. But I have the same complaint that everyone who's loved a cancer patient has: *It's so unfair*.

Still. The patients I spoke to share my mother's attitude: "I am very, very lucky," Hollub told me. "My oncologist calls me his outlier." Ornstein, who now works for Discovery to Cure, a Yale School of Medicine program devoted to the prevention, early detection, and treatment of gynecological cancers, says: "I'm lucky. The average ovarian cancer patient sees four to six doctors before getting a diagnosis," while she was admitted to a hospital for cancer surgery three days after walking into a clinic with a terrible stomachache. "I'm blessed the way my life has turned out," Ornstein adds. "I'm able to take my disease and help make other peoples' lives better." ■

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Spotlighting Our Cancer Vulnerability

Launched in *Lilith*'s Fall 2019 issue (available in print or at Lilith.org), and continuing over the next few months, the magazine is publishing first-person accounts of Jewish women's experiences of breast and gynecological cancers, commentary by scientists, resources for diagnosis and recovery, and a curated online selection of reports from the *Lilith* archives. This focus is made possible with the support of the Sherril Ann Siegel Memorial Fund, under the auspices of the Alpha Omega Foundation. Further information at Sherril Ann Siegel Memorial Fund, 1234 19th St. NW, #306, Washington, DC. 20036.