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## Breast cancer's crystal ball: Young Jewish women face down the disease

by stacey palevsky  
staff writer



Three months before their wedding, Tracey Gropper and Thom Downing lay in bed, with piles of paperwork from the fertility clinic strewn across their comforter.

At a time they should have been focused on planning their interfaith wedding ceremony, they instead were pouring through papers detailing how Tracey's eggs could be harvested, should her upcoming chemotherapy make it impossible for her to get pregnant naturally.

It was an evening in December 2003. Tracey's chemotherapy was to begin in a week. The house was quiet when she stopped reading, turned to her fiancé and broke the silence by asking him a soul-shattering,

“what if.”

If she didn't beat the cancer, would he want to raise their children without her?

This was not a question she ever thought she'd have to ask — especially as a 29-year-old.

But after being diagnosed with cancer, after learning she carried a genetic mutation that would make a recurrence likely, after dozens of doctor's visits, and after accepting that her thick brown curls would fall out — after all of that — it was a question she had to ask.

Thom's eyes filled with tears.

“It was a very intimate moment of me asking: Are you sure you want to [start a life together], are you sure you're on board?” she recently recalled. “We were both emotional.

“And he said to me, ‘If you weren't here, I would want as much of you as I could keep.’”

Tracey Downing, of Redwood City, is one of thousands of young women who carry a genetic mutation that gives them a 50 to 85 percent chance of getting breast cancer.

The genes, known as BRCA1 and BRCA2 (an abbreviation for breast cancer 1 and breast cancer 2), are known as tumor suppressor genes — when working properly, they help prevent cancer. But mutations in the two genes can actually make people more susceptible to developing certain types of cancer, including breast cancer.

Ashkenazi Jewish women are 13 times more likely than non-Jewish women to carry one of these hereditary genetic mutations. Studies indicate one in 40 Ashkenazi women carry mutated BRCA1 or 2 genes. In the general population, only one in 500 carry these mutations.

Despite these alarming statistics, most Jewish women are unaware of their increased cancer risk, Downing said.

“I think it still comes as a complete surprise that the breast cancer gene [mutation] is more common in the Ashkenazi population,” she said.

Now, five years after that wrenching conversation about the future, Downing is cancer-free. She and Thom married under a chuppah Feb. 14, 2004 in Cabo San Lucas, Mexico. The wedding was “wigs optional.” Many of the guests wore wigs or shaved their heads in honor of the bride’s battle with cancer, which had left her bald due to chemotherapy.

They took their honeymoon in November, nine months after the ceremony. The month was chosen with intention: It was a way to commemorate just how much they had endured and how far they had come since Downing’s diagnosis one year earlier.

The couple marked the transition from hard times to better ones by creating their own mikvah off the coast of Turtle Island in Fiji. They entered the warm sea and submerged three times. It was a “powerful” experience, said Downing: She felt liberated, as though the saltwater had rinsed away the previous year’s pain.

One month later, she became pregnant.

Though Downing is an advocate for genetic testing, she readily admits, as do counselors, that finding out the results can be painful and emotional.

“We see quite a few people who aren’t sure if this is information they really want to know,” said Nicola Stewart, a genetics counselor with the Cancer Risk Program at the UCSF Helen Diller Comprehensive Cancer Center.

“The emotional layers involved in getting the results, and the choices that then need to be made, are very profound.”

Downing learned shortly after she was diagnosed with cancer that she had the BRCA1 genetic mutation. It was just one year after her mother, a breast cancer survivor, found out she carried the gene.

Downing’s older sister, Joelle Kaufman, learned she had the genetic mutation in 2005. When Kaufman, who lives in San Mateo, went to get the results of her test, Downing went with her.

Kaufman, 38, has not had cancer. Yet last summer she opted to have her ovaries and fallopian tubes removed, forcing her body into early menopause. It was worth it, she said, because the procedure halved her risk of getting breast cancer and lowered her risk of ovarian cancer to just 2 percent.

“Breast cancer is a machine,” Kaufman said. “And until you get in the driver’s seat, somebody else is.”

Women with the BRCA1 or 2 genetic mutations also have an increased likelihood of having melanoma and ovarian cancer. Men with the gene mutations have an increased risk for breast and prostate cancer.

About 5 percent of the general population has a hereditary form of cancer; in the Jewish community, that number is closer to 30 percent.

Downing's mother was diagnosed with cancer as a 36-year-old in 1983. At the time, no one had heard of BRCA1 and 2.

Because of her mother's cancer, Downing expected she'd someday get it too. But she never dreamed she'd find a lump under her right arm just weeks after she and Thom completed an Ironman Triathlon in British Columbia.

The lump, first thought to be benign, turned out to be cancerous. "I get scared every once in a while," she wrote in an e-mail to friends in 2003. "I get a little panicked thinking about that first chemo treatment but keep telling myself 'You have to start in order to finish.' As much as I wish this wasn't happening, it is and you have to do what you have to do."

Since the 1994 discovery of BRCA1 and 2 mutations, young women like Downing and Kaufman have had the opportunity to do what their mothers could not: They are able to flip their genetic cards onto the table, then make appropriate choices to reduce their cancer risk.

Those choices include extreme measures such as removing one's breasts or ovaries, and moderate ones such as drug therapy or careful screening to catch and treat the cancer at an early stage.

Downing's doctors encouraged her to have a prophylactic double mastectomy (removing both breasts), but she refused. She couldn't imagine being a mother and not being able to breast-feed.

"I figured that if I removed my breasts, I couldn't reverse the decision. But if I kept them, I could change my mind at any point in the future," she said.

Instead, she had a lumpectomy (during which surgeons removed the cancerous mass and surrounding cells) and went through 16 weeks of chemotherapy treatments every other Friday night — after which friends and relatives would come over for "chemo parties" to keep her and Thom in good spirits.

Since then, she has been vigilant, getting mammograms twice a year and an MRI once a year. Before turning 40, she expects to have her ovaries removed.

Other women immediately opt for preventative surgery, which can reduce the risk of breast cancer to between 5 and 8 percent — below the 13 percent odds of getting breast cancer in the general population.

Mara Langer, 40, has had cancer twice, the first time when she was 30. She had both her breasts removed after her first cancer diagnosis.

"To have my body change was really big for me to overcome," said the San Mateo resident.

Langer, an only child raised by a single mother, was 11 when her mother was diagnosed with breast cancer. During the five years her mom fought and eventually lost her battle with cancer, Langer was "the one who went to the doctors' appointments and held her hand, who was up at midnight, massaging her head."

While surrendering her breasts was difficult, it was a choice that Langer said was ultimately "empowering."

"You finally have a way of making a decision, of getting in front of the cancer and telling the cancer, 'I'm taking care of this. I'm getting every last morsel of you out of me.'"

But knowing your genetic makeup is both a gift and a curse.

Raychel Kubby Adler, 36, said after she learned she had the BRCA2 mutation, she felt like it was a “ticking time bomb inside me.”

The Davis resident suspected she was predisposed to cancer, based on her family history. Her mother was diagnosed with breast cancer at age 54, and died of lung and brain cancer at 69.

Adler’s older sister, Lisa Kubby, 52, was diagnosed with breast cancer at age 36, two years before BRCA1 and 2 mutations were discovered.

At the time, however, Adler was an undergraduate at U.C. Santa Cruz, and feeling the invincibility of most 20-somethings. She was young and healthy. Genetic testing wasn’t on her horizon.

Kubby had a mastectomy and her cancer went into remission for several years. But three years ago, the cancer returned, this time in her lungs.

Adler, who had become a mother of two, suddenly felt an urgent need to know her own genetic makeup.

Genetic testing means accepting responsibility for the outcome of that test. Women who find they carry the gene mutation must decide how that knowledge will shape their lives, their choices, their families.

“Part of what’s challenging is that there are so many options, it’s overwhelming,” Adler said.

After getting her results, Adler decided to schedule a double mastectomy and reconstructive surgery, which she’ll have in December. She has chosen to have the kind of reconstruction in which doctors use a woman’s abdominal tissue to rebuild the breasts (as opposed to artificial implants or no reconstruction at all).

Meanwhile, Adler’s sister Lisa has lived with advanced metastatic breast cancer for the past three years.

Adler sees her surgery as a chance to “live without the looming shadow of breast cancer.

“It’s almost like a gift to both of us, to know that I have the opportunity to take a different path,” she added. “Lisa is an amazing fighter, she’s a hero to me, but I want her to see that I can have a different future.”

Sarah Fenner, now 41, was 34 and the mother of two children when she found a lump that felt like an “unshelled almond” beneath the surface of her skin. She was stunned.

“I didn’t know what to do. There’s no ‘I-found-a-lump-in-my-breast’ listing in the phone book,” she said.

After discovering she had stage 2 invasive ductile carcinoma, Fenner decided to get tested for the BRCA1 and 2 mutations, even though her family had no history of cancer. She learned she had the BRCA2 mutation. Armed with that knowledge, she decided to have both breasts and her ovaries removed.

“It’s miserable to be in menopause at 35,” she said. “But for me, it was an insurance policy I couldn’t turn down.”

Preventative surgery “is certainly not for everyone,” Fenner said. “But it was absolutely the right decision for me.”

The breast cancer road is especially bumpy for young women like Adler or Downing.

“There are very unique concerns for younger women, compared with someone who’s been married for 20 years and already has kids,” Downing said.

When she was diagnosed with cancer, “there were so many questions, and unfortunately, there wasn’t a lot of information about what to do with someone my age,” she recalled. “I knew I wanted to have children — would that be possible? ... I was 29, I had never tried to get pregnant, so I had no way of knowing.

“I felt a lot of guilt. I kept apologizing to Thom that he got stuck with a lemon. And now we have a daughter, and we have to worry about her, and he didn’t choose that when he fell in love with me.”

Parents with BRCA1 and 2 mutations also wrestle with how and when to explain their genetics to their young children. Adler’s daughters, ages 2 and 5, know that Mommy will soon be having surgery, but they don’t know why.

“At what point do I talk to them? At what point do they get tested?” Adler asked. “I want [my daughters] to live out a normal childhood and adulthood. God willing, something will be different by that point.”

Beyond that, women must consider when — or if — to have preventative surgery if they haven’t yet had children. They must think about how to share their genetic information with a new romantic partner, and whom to go to for advice?

“I was navigating unfamiliar waters. I had never known anybody my age with breast cancer,” Downing said. “And I didn’t fit into the ‘typical’ breast cancer population. It didn’t help me to talk to 50- or 60-year-old women, because I was in a different situation.”

Added Fenner, “You’re in a different headspace than women who’ve been married for 45 years. There’s a different level of vulnerability.”

Fenner also struggled with the misconception that breast cancer occurs only in middle-aged or elderly women. She knew she wasn’t the only young woman with breast cancer, yet she was the only woman under 50 in her hospital’s support group.

“I was really public about my cancer,” she said, “because I needed to put a face on breast cancer that wasn’t your grandmother’s.”

Fenner works at Congregation Kol Shofar in Tiburon. Her husband is a rabbi at the Bay Area Jewish Healing Center. She said she could never have gone through chemotherapy, radiation and preventative surgery without the support of their Jewish community.

The Gemilut Chasadim (acts of lovingkindness) committee at Kol Shofar brought the Fenners meals three times a week for a year and a half.

“It’s hard to be in a place of willingness to ask for help, but it was not possible for me to do it all,” she

said. “Treatment can be a full-time job, and having help allowed me to be the things no one else could be for me — a wife and mother.”

Many young Jewish women who have the BRCA1 or 2 mutations have chosen to be advocates for breast cancer prevention.

In two weeks, Adler will run the Big Sur Half Marathon, for which she raised \$5,000 for FORCE (Facing Our Risk of Cancer Empowered). As a professional wellness coach, she also has reached out to other young women with breast cancer, to help them make healthy choices in the midst of what feels like “an incredibly overwhelming” diagnosis.

Langer, meanwhile, raised \$12,000 for the Avon Breast Cancer walk. Last year, she arranged for a genetics counselor to speak to her Rosh Chodesh group about the risk of breast cancer in Ashkenazi women.

Langer is also an active member of Sharsheret, a national nonprofit that educates Jewish women about their cancer risk, and networks Jewish women with the breast cancer gene mutations or a breast cancer diagnosis.

Four years after Tracey and Thom Downing immersed in an ocean mikvah in Fiji, they are parents to Jacob, 3, and Emma, 1.

Downing breast-fed both children.

“Being able to breast-feed was restorative — it was what I fought for,” she said.

While the cancer had made her feel betrayed by her body, “getting pregnant restored my belief in my body and what it’s capable of.”

She’s certain that keeping her breasts was the right choice. And yet, she would never tell anyone with BRCA1 or 2 mutations how to proceed after hearing those test results.

“It’s a very personal decision,” she said. “Nobody else walks in your shoes.”

### **Genetics counseling can help with decisions**

Naomi, a 32-year-old single Jewish woman from Berkeley, was carefree until she found out her mother — a seemingly healthy, active woman and practicing physician — had advanced breast cancer and would need a mastectomy, chemotherapy and radiation.

A few months later, her mother tested positive for the BRCA2 genetic mutation.

Like mother, like daughter? Naomi wasn’t sure she wanted to know.

Naomi, who preferred her last name not be used (fearing her genetic information might impede a future job search), is wrestling with the decision of whether to get tested for the BRCA1 and 2 mutations.

Over the past two months, she has spoken with two gynecologists, a breast surgeon and a genetics counselor — but still can’t decide if she wants to know if she’s genetically predisposed to breast cancer.

“I’m not afraid to find out,” she said. Rather, the scarier part is “what I’m going to do with the information once I have it. Knowing I have this gene opens up a whole new round of questions.

“I don’t have kids. I’m not married. Do I have a preventative mastectomy? I’m not ready to make that decision.”

Naomi’s quandary is not uncommon, said Nicola Stewart, a genetics counselor with the Cancer Risk Program at the UCSF Helen Diller Comprehensive Cancer Center.

She counsels many women who are not sure they’re ready to receive the results of a genetic test.

“But I think they soon realize the power that this information can have,” she said. “They can know more specifically what their risk is, and also how to do something about it.”

In the last five years, the number of people testing for the BRCA mutations has increased by 50 percent every year, according to Myriad Genetics, which patented the blood test for the mutation about 12 years ago. About 70,000 men and women tested last year.

Only about 20,000 of the estimated 600,000 gene carriers have been identified. Of those 600,000 carriers, about 150,000 are Jewish, mostly Ashkenazi. Other ethnic groups, such as French Canadians and Filipinas, also have a genetic predisposition.

About 95 percent of Ashkenazi Jews who have a mutation have one of three common types, which means the mutations are easier to find and the test costs much less — about \$400, as compared to \$3,000 for a test that analyzes the entire gene.

Most insurers cover genetic testing and some genetic counseling. Federal and California law provide fairly good protection against genetic discrimination from insurers, stipulating that a genetic predisposition cannot be considered a pre-existing condition. But individual policies are not as well protected as group policies.

Insurance companies usually cover preventative surgery, since removal of the breasts and ovaries is considered an accepted course of treatment for women carrying the BRCA1 or 2 genetic mutations. Though the surgery is expensive, it is less costly than treating the cancer that would likely grow without the surgeries.

When people come to see Stewart for counseling before getting a genetic test, she first outlines their family tree. She asks: Which relatives had cancer? What kind? When were they diagnosed?

Those answers help determine whether or not someone is a good candidate for testing.

Generally, genetic counselors will recommend testing if any first-degree relatives (parents, siblings, children) have had breast or ovarian cancer, or if at least two second-degree relatives (aunts, uncles, nieces, nephews, grandparents) have had the disease.

Stewart’s clients return to her to receive their results. If a patient tests positive for BRCA1 or 2 mutations, she helps them decide how to talk to their relatives about their results.

“In genetics, the whole family is your patient and responsibility,” Stewart said.

The **L.A. Jewish Journal** contributed to this report.

**Want to know more about hereditary**

**breast cancer?**

Check these Web sites:

**Sharsheret**

[www.sharsheret.org](http://www.sharsheret.org)

**FORCE: Facing Our Risk of Cancer Empowered**

[www.facingourrisk.org](http://www.facingourrisk.org)

**Chicago Center for Jewish Genetic Disorders**

[www.jewishgeneticscenter.org](http://www.jewishgeneticscenter.org)

**Young Survival Coalition**

[www.youngsurvival.org](http://www.youngsurvival.org)

**Healthy Young Attitude**

[www.healthyyoungattitude.org](http://www.healthyyoungattitude.org)

**National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)

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