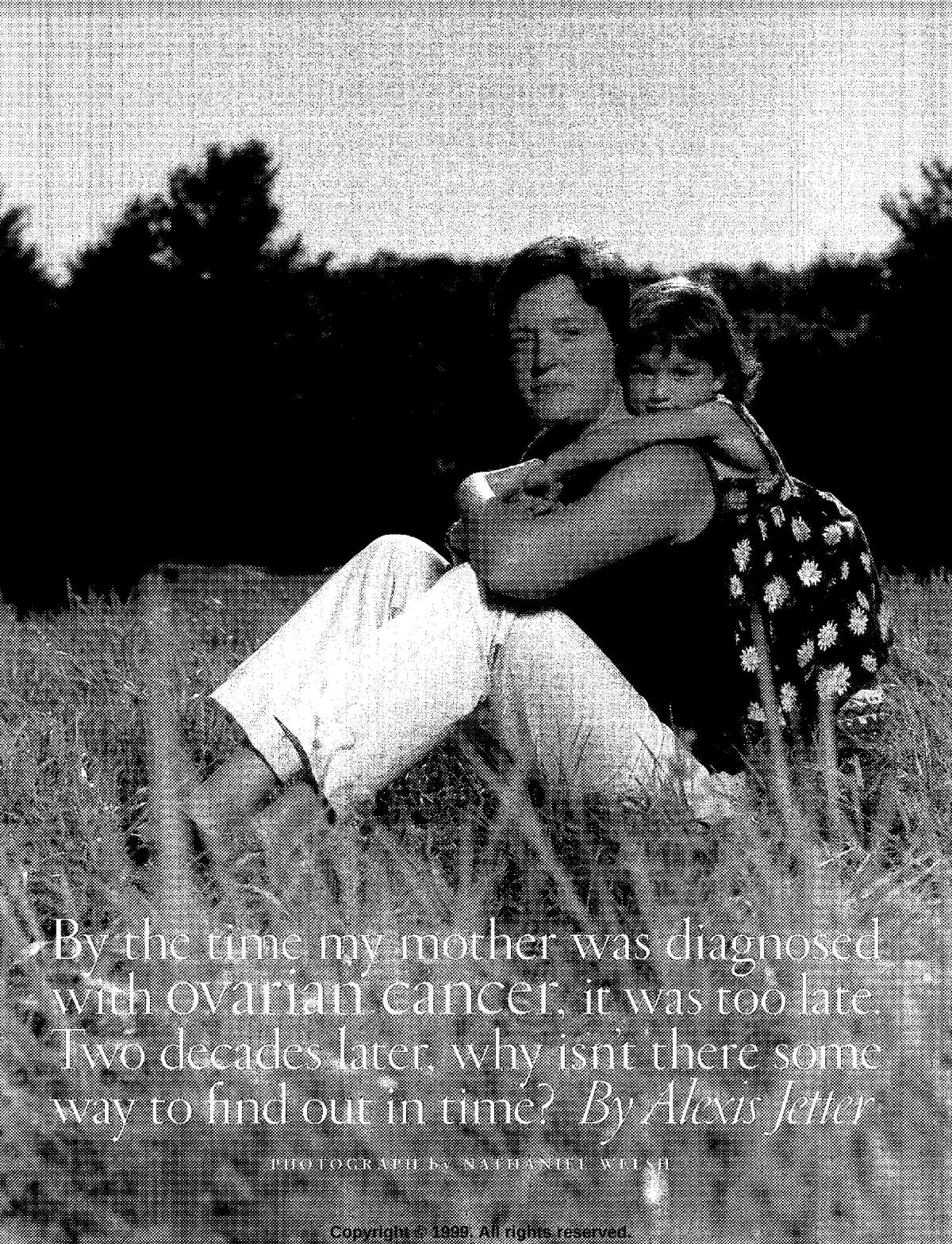
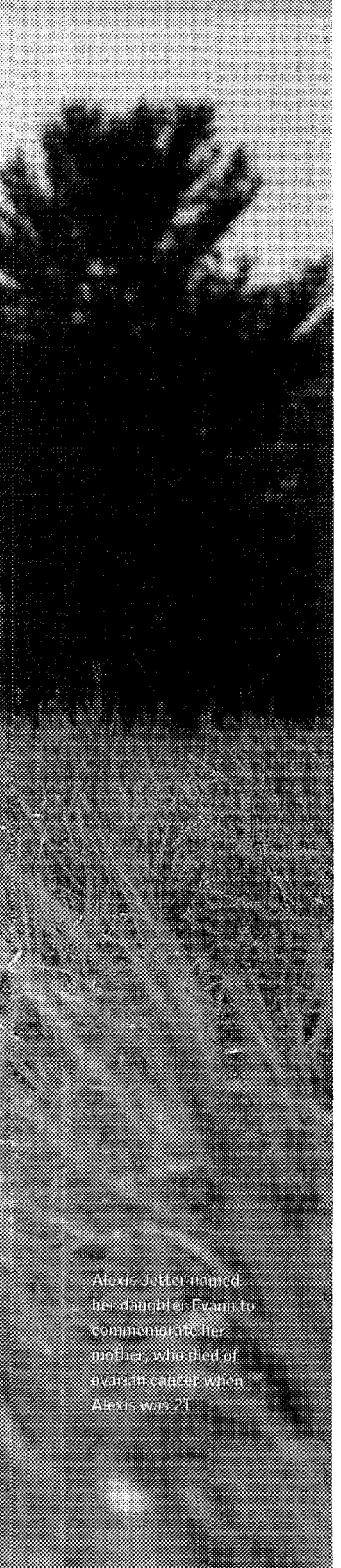


By the time my mother was diagnosed with ovarian cancer, it was too late. Two decades later, why isn't there some way to find out in time? *By Alexis Jetter*

PHOTOGRAPHS BY NATHANIEL WELSH



Alexis Jetter named her daughter Evann to commemorate her mother, who died of ovarian cancer when Alexis was 21.

My Mother

THE OBITUARY IN THE MORNING PAPER JOLTED ME QUEASILY AWAKE. "Elizabeth Tilberis, Magazine Editor, 51, Dies."

Fear and remembrance entwined like a tumor around my gut. For years Tilberis, the much-admired editor of *Harper's Bazaar,* had defied ovarian cancer, turning her private struggle into a public crusade. She'd pushed for greater awareness of the illness, raised money for medical research, and written a punchy, funny memoir, *No Time to Die: Living With Ovarian Cancer.* I, like millions of her readers, assumed she had won her battle.

I hadn't realized how much I'd been counting on it. Twenty years ago, my mother, too, died of ovarian cancer. She was 52. Back then, doctors could do little when the disease spread to her abdomen, spawning tumors that blocked her intestines and literally starved her to death.

That loss still aches. But why was I so upset about the death of Tilberis, a

My Daughter

relative stranger? Apparently, I wasn't alone; her death stirred an outpouring of grief. "Liz was the Joan of Arc of ovarian cancer," says Carolyn Runowicz, professor and director of gynecological oncology at Albert Einstein College of Medicine and Montefiore Medical Center in New York City. "She lent an air of invincibility: She was going to fight this and live forever."

I'd met Tilberis, just once but memorably. With a grand smile, she came sweeping out of her office to greet me and my infant daughter after I'd written an article about lesbian motherhood for the magazine. Tilberis had just had a bone marrow transplant, leaving her pale and rail thin, but she betrayed not a hint of frailty. She stuck out her hand and gave me a firm handshake. "And this must be Evann?" she asked with delight, her British accent warm rather than clipped. Something about her matter-of-fact beauty, her dignity, and her strong, sculpted hands reminded me of my own mother, Evelyn.

I thought of those hands again as the obit swam before me. But now an icy fear mixed with the familiar grief. Why was ovarian cancer still so deadly? How

My Risk

could Liz Tilberis, treated with the most sophisticated medical technology, fall victim to it today? Was I, too, at risk? Putting down the newspaper, I closed my eyes, my thoughts rushing back 20 years to my mother—and then to my daughter, who, like me, may be vulnerable to "the disease that whispers."

EVELYN JETTER, engineer, inventor, and mother of four

IN DECEMBER 1979, a blizzard struck Manhattan, delaying me for frantic hours as I rushed to see my mother. The flakes seemed to fly upward outside her hospital window. I saw her drawn, dull-eyed face and realized that she was going to die. Stepping out into the hallway, I fell into the arms of a nurse, who already knew.

I was the daughter from the West, summoned by my mother's whispered surrender. She hadn't wanted me to come. She wanted to meet midway across country for a victory hike. That would be in Death Valley, she wryly observed in her final letter to me.

14 Nov. 79
Dearest Lex,
This small still voice comes to you from the depths of my small intestine. By now I've become a Dr. Seuss creature who lives on the mercury droplets inside the rubber balloon at the leading tip of an orange snake. The dragging end emerges from my left nostril. . . .

Let's plan something I can look forward to—I find that a real help. Right now I'm hoping for cranberry jello for Thanksgiving. . . .

Much, much love
Mom

I had no idea then of the threat ovarian cancer poses. In the United States it strikes one woman in 58, and more than half die within five years. It kills more women than all the other gynecological cancers combined. That doesn't have to be the case: If her disease is caught in Stage One, when it's confined to the ovaries, a woman has a 95 percent chance of long-term survival. But only about one case in four is detected early, and that's usually due to luck.

Most often, symptoms appear only after cancer has spread throughout the abdomen. At that point, survival rates drop precipitously. About 60 percent of women diagnosed with ovarian cancer have advanced disease, and only 28 percent of them are alive five years later.

I'm told this represents progress. Twenty years ago, the mortality rate was even higher. But the vagueness of symptoms remains one of the biggest barriers to detection and survival. Fatigue, a generally lousy sensation, feeling full after eating very little—these "warning signs" are also common in healthy women. Even such clues as abdominal swelling, pelvic pressure, and gastrointestinal problems are easily ignored. Frequently, women diagnosed with ovarian cancer say they were initially told by doctors to go home and take Maalox.

"We can tell you story after story of women who had classic signs of disease and were dismissed out of hand," says Ann Kolker, an ovarian cancer survivor and executive director of the Ovarian Cancer National Alliance, an advocacy group. "This disease is barely on the

Can You Lower Your Risk?

Ovarian cancer is a stealth disease, but the choices a woman makes may help her move beyond its reach. Here's what researchers know about lifestyle changes that may improve your odds.

HAVING CHILDREN is the most protective step a woman can take—although it's not the kind of decision anyone would make in the name of disease prevention. The surface of the ovary ruptures during ovulation, and researchers think that a breakdown in the repair mechanism sometimes leads to cancer; pregnancy usually interrupts ovulation for at least a year. The first time a woman gives birth, she lowers her risk by 40 percent. Each succeeding birth reduces it by about another 15 percent.

TAKING BIRTH CONTROL PILLS also prevents ovulation. Researchers know that women who took the old-style high-estrogen Pill for at least five years cut their risk by 50 percent; it's thought that the newer low-dose Pills also provide some protection.

EATING WELL may shave risk. Though all the evidence isn't in, some studies hint that a diet high in fruits and vegetables and low in saturated fat affords protection.

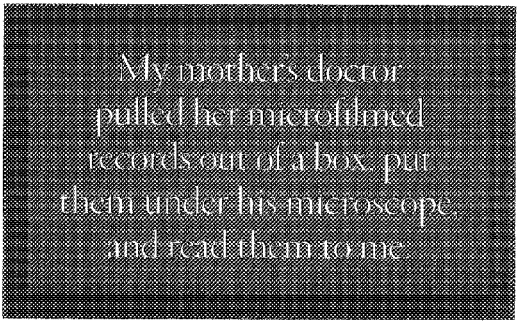
AVOIDING TALC may be a good idea. There's some evidence that women who use talcum powder on their genital area or diaphragm raise their risk. Cornstarch is a safer alternative.

DON'T PANIC if you've used fertility drugs. Although some studies suggest danger in the drugs, which boost the number of eggs released at ovulation, in other studies they appear harmless. Instead, infertility itself may sometimes be the culprit. If the drugs do add to risk, the increase seems to be small.

TAKING ACETAMINOPHEN is a surprising recent addition to the list. In one study women who took the analgesic daily for ten years halved their risk. If further studies bear out this unexpected benefit, women who are at higher-than-average risk of this cancer may start to think about taking a daily acetaminophen. It probably won't hurt and might help.

radar screens of women or their physicians."

That was certainly the case for my mother and her doctor. But now, as I sift through her letters and notepads of scribbled thoughts and equations—she was an engineer and inventor, always knee-deep in data—I can trace the shadowy outlines of cancer. "Intermittent first appearance, Oct. 1976," she wrote later in her red date book.



Her stomach had started to bloat for no apparent reason. She noticed it in Bonaire, a Caribbean island where she'd gone scuba diving with fellow engineers. At 49 she had learned to dive, and this was her first underwater adventure. The bloating was embarrassing, my mother told me later, but she was able to hide it—from her colleagues, from us, even from herself.

In my family, illness was something to be ignored until it lost interest and went away. My mother had no patience for her body's shortcomings. She returned home from Bonaire to a New Jersey winter, so it was easy to wear her oversize ski sweater much of the time. It hid the bloating; a lab coat did the same at work.

For years I thought that my mother had neglected her symptoms. But when I asked my father recently, he wasn't sure. Suddenly it was important to me. I called my mother's former gynecological oncologist, Robert C. Wallach, now at New York University School of Medicine. His secretary warned me it would take forever to locate records that old.

But Wallach called back an hour later.

"I remember your mother," he said. "What do you need to know?" That night, he pulled my mother's records out of a box of microfilm, put them under his microscope, and read them to me.

My mother hadn't ignored her symptoms, after all. She went to see her regular gynecologist a month after she first noticed the bloating. Oddly, according to her records, he gave my mother a tubal ligation and sent her home. It's unclear why my mother, then 49 and approaching menopause, chose to be sterilized.

But here the account grows doubly puzzling. The gynecologist found something alarming during surgery: an accumulation of fluid, known as ascites, in my mother's abdomen. Produced by tumors, ascites is a red flag for ovarian cancer and probably caused my mother's bloated stomach. But the doctor didn't

tell her about the ascites. Nor did he tell her that the fluid was found to contain cancer cells. Or that he'd discovered numerous lesions on her bowel and uterus, signs that the cancer had spread.

By February 1977 my mother had grown so weak that one night she had to ask a colleague to drive her home from work. That's when she went to Wallach. She told him of the bloating and the sensation of fullness in her stomach. He examined her, analyzed the pathology slide from her tubal ligation, and operated within days, removing her uterus, ovaries, and some abdominal tissue.

A few days later my father, two brothers, sister, and I gathered in a hospital room where my mother told us the news. "I have ovarian cancer," she said calmly. We had no idea how sick she was, and her demeanor gave no clue. Privately, she knew her odds were slim.

I now know that her cancer had progressed to Stage Three, meaning it had invaded her abdomen. ("At Stage Four," Tilberis writes in her memoir, "they tell you to go home and get your affairs in order.") But Wallach said the surgery had gone very well. My mother urged us to assume the best.

Instead, things got worse.

Hi Dexter, she wrote in June 1978, using her pet name for me. *First, a quick trip through cancer space. The first report of no recurrence was a bit hasty. Some microscopic cells were found in the biopsy search. They are changing my poison. . . . Will keep you posted.*

Always a restless spirit, my mother now indulged her wanderlust. She stored a tent in the trunk of her car, hiked through Yosemite, and drove cross-country with me in a beat-up rented Mustang. On her return flight she wrote:

Dearest Lex,
You must know this trip was memorable and significant in many ways for me. This morning, returning to the airport, I felt a real sinking at the termination of it. I agree with you on squeezing in all we can.

My mother died less than two years later, still thirsting but ready to go. "The West is calling—and I don't mean California," she wrote to me from her hospital bed, her exuberant handwriting reduced to cramped, weak letters. "'Nuff small talk," she signed off. "I'm disappearing into that colon again."

After she died, we piled into a taxi outside the hospital, each holding a shopping bag of the unfinished lab reports she'd kept by her bedside. We still can't bear to throw them away.

I AM MY MOTHER'S DAUGHTER. I can see that just by looking around my basement office, a dusty, teetering landscape of half-read books, half-filled yellow notepads, and unrepairable gadgets.

Outwardly, the likeness to my mother ends there. I lack her cheekbones, height, elegance, and tact. But as I began to research the disease that took her life, I started to wonder if there might be some similarities I wish I didn't have. Nearly one in ten cases of ovarian cancer is hereditary. Just how much of herself has

(continued on page 188)

my mother passed on to me?

After decades of research, scientists still don't know what causes ovarian cancer. But they suspect it has to do with incessant ovulation. Every month an ovary erupts, releases an egg, and heals. If a woman takes no breaks from ovulation—if she has no children and doesn't use birth control pills—she will weather perhaps 444 rupture-and-repair cycles by her 50th birthday. In some women the repair mechanism may break down, enabling abnormal cells to grow. Ovulation run amok, one writer put it.

There are a few suspected risk factors, although many women who get the disease claim none of them. I fit a few too many for comfort. Women who have never or rarely given birth are more likely to develop ovarian cancer; I have only one child. Women who have used oral contraceptives for five years appear to cut their risk of the disease by half; I've never used them. Women whose mothers or sisters had the disease are at a higher risk; I certainly fit that category.

But I've never had breast cancer, which would double my risk. And ovarian cancer is most prevalent in women over 55. Yet the women I've known with the disease—my mother, Tilberis, a few friends—were diagnosed much earlier. At 41, I'm only eight years younger than my mother was when her symptoms appeared.

So I quickly came up with a plan: I would get tested for the disease, and if the test delivered bad news, nip it in the bud. Just as quickly, I realized it wasn't so simple—because there is no good test for ovarian cancer.

The problem is rooted in anatomy. The ovaries are small, well-armored organs floating free in a cavernous space. A healthy premenopausal ovary is about five cubic centimeters. A postmenopausal ovary is a little smaller—roughly the size of an almond, says Carmel J. Cohen, director of gynecologic oncology at New York's Mount Sinai—NYU Health System. A cancerous ovary, even one that contains a billion cancer cells, swells only to the size of a walnut.

So a routine pelvic exam rarely catches early-stage disease. "You're trying to distinguish between an almond and a walnut," says Cohen, "in a woman whose almond is located halfway between her front belly wall and her backside, after she's just had a big lunch and she's on her way to the baby-sitter and the doc is an hour behind schedule."

Pap smears can't pick it up, either. For that matter, even a surgeon looking at an ovary can't tell whether it's cancerous. The only way to know if an ovary should come out is to remove it and send it to the lab for testing. Most women aren't willing to take such a draconian step.

> A surgeon examining an ovary can't tell if it's cancerous. The only way to know is to take out the ovary and send it to the lab.

In fact, there *are* two tests for the disease, a blood test and a vaginal ultrasound exam, but they aren't recommended for the average woman because they often give erroneous results.

The blood test measures levels of the CA-125 protein, which is secreted into the bloodstream by ovarian cancer cells. As it happens, though, CA-125 levels can be elevated by any number of factors, including pregnancy and menstruation. That's one of the frightening drawbacks of the test: It can convince healthy women that they have ovarian cancer. Some women have had their ovaries taken out, in a procedure called an oophorectomy, only to find that they hadn't had cancer after all.

I was even more worried about the test's other major shortcoming: CA-125 levels can look normal in women who have the disease. Studies have shown that the test detects early-stage ovarian

cancer less than half the time.

"There is no evidence—none, zero—that wide use of the CA-125 test will reduce the mortality rate of the disease," says Maurie Markman, director of the Cleveland Clinic's Taussig Cancer Center. "But we sure have evidence that we'd have unnecessary tests, unnecessary anxiety, and unnecessary surgery."

That didn't sound so good. But the blood test's reliability goes up if it's paired with the ultrasound exam. The procedure is much like the sonogram women have during pregnancy, except that instead of resting atop the belly, the probe is placed in the vagina to get closer to the ovaries. And doctors aren't looking for a baby.

This ultrasound is better than CA-125 at detecting early-stage disease. John van Nagell, director of the University of Kentucky's ovarian cancer screening project, has used ultrasound to monitor 15,000 women for a dozen years. To date, he's found 20 previously undetected ovarian cancers. Fifteen of the women had early-stage cancers, and all are alive today.

Unfortunately, ultrasound isn't able to distinguish between a malignant tumor and a benign growth. In van Nagell's study, nine out of ten women who had

Coming Soon

Tests to Catch a Killer

Given the flaws of the current screening tests for ovarian cancer, it's no wonder doctors don't recommend them for women at average risk: They can signal disease in a healthy woman and miss cancer that's there. But researchers say tests that are now under study may change all that.

BETTER BLOOD TESTS. One of the most promising procedures is a simple blood test that measures levels of a protein called lysophosphatidic acid (LPA). Studies suggest LPA is necessary for the growth of ovarian cancer cells, and it looks like the protein is detectable very early in the life of the cancer. Oncologist Maurie Markman, of the Cleveland Clinic, tried the test in 165 women with ovarian cancer. The test flagged all the women whose cancer had spread and nine out of the ten patients whose cancer was still confined to the ovaries. By contrast, the current blood test, for CA-125, misses more than half of all early-stage cases. More research must be done before hopes get too high. But 15 other blood tests are now under development, with similarly promising results.

AN OVARIAN PAP SMEAR? Another sort of exam may someday ensure that no woman has her ovaries removed only to find they were healthy. One of the many frustrating aspects of diagnosing ovarian cancer is that a malignancy can't be ascertained with the naked eye. The so-called ovarian pap smear is the brainchild of David Fishman, director of the Ovarian Cancer Early Detection Program at Chicago's Northwestern University Medical School. The test requires scraping the ovaries during laparoscopic surgery, then examining the cells under a microscope. "Under the microscope," says Fishman, "you always know." Fishman and his colleagues recently collected tissue samples from 60 women who'd had their ovaries removed because of cancer or benign conditions like painful cysts. The researchers sent the ovaries to one pathologist and the scrapings to another. In each case, the diagnoses matched.

The ovarian pap smear is an invasive procedure, and certainly not one that a healthy woman would make routine. But Fishman isn't aiming at all women—just those at high risk for ovarian cancer. If you're at increased risk and are interested in finding out more about early detection studies, call the National Cancer Institute at 800/422-6237.

their ovaries removed turned out *not* to have cancer.

It's unclear, though, how many of those surgeries were truly unnecessary. Many of the "benign" growths showed signs of being precancerous. And without testing, far more cases of ovarian cancer would be missed. In fact, van Nagell thinks ovarian cancer screening will eventually take its place beside the mammogram as a yearly exam for the average woman over 50. "Women are going to demand it," van Nagell told me.

I found myself agreeing. Give me the information, I told my doctor. I can handle it.

The CA-125 test was undramatic: I had blood drawn. The ultrasound, by contrast, started out fun, as I watched my innards come to life on the television screen. Halfway through it, however, the boyish, friendly doctor frowned at the screen, muttered something to a nurse, and sent for the older, more experienced guy in the bow tie.

I found myself crying softly in the darkened room as I waited. Did I have my mother's cancer?

It turned out to be nothing, just one of my organs pretending to be more than it was. Still, the scare made me a little more sympathetic to the "don't test" argument, which boils down to a concern that women will demand the tests in numbers out of balance with the incidence of the disease, and then get unnecessary, life-altering surgery.

But I resent the notion that women should be spared the shock that a faulty test might give them. Is it legitimate to withhold screening in order to protect women from worry? "By that argument, you'd never see a doctor," van Nagell says. "You'd never have a mammogram."

HAPPILY, BOTH MY TESTS turned out negative. But I still had to navigate one more morass. Researchers had told me that my mother's cancer approximately doubled my risk, to about 5 percent. Things would be worse, they said, if I had an extensive family history. I knew that none of my mother's immediate relatives had the disease. But she didn't have many female relatives, period. Most of the women in her Hungarian family had died in Nazi concentration camps. On her mother's side, she had two healthy female first cousins. On her father's side, only one female first cousin survived Auschwitz. I'd never spoken to her, but I got her number from my aunt.

Eva,* it turned out, had also been diagnosed with ovarian cancer. Fourteen years ago, at age 58, she'd gone to her doctor, complaining of abdominal pain and distention.

Don't worry, he told her. It will go away. Eva's son, an internist, wasn't so sure. "He banged on my abdomen with two fingers, and he didn't like what he felt," she said. "Then I got worried, because he never was an alarmist."

> "If I were you, I'd have the test done next week," my mother's old doctor told me. "And if it's positive, I'd check myself into a hospital."

Eva had Stage Three ovarian cancer. She survived only because of the watchfulness of her son, the doctor. "But thank God, knock on wood, I'm fine," she said.

That made two women in my family with ovarian cancer.

I called Steven Narod, head of the hereditary cancer program at Women's College Hospital in Toronto. Narod has the breezy, offhand manner of a slightly bored mortician. Even with a mother who died of the disease, I had little to worry about, he assured me; the addition of a cousin didn't qualify as an "extensive" family history. "The nice thing in cases of ovarian cancer at age 52, with no breast cancer in the family—and you're not Jewish, presumably?"

"I am Jewish," I said, my voice flat.

"Oh, if you're Jewish, the risk of having a genetic mutation jumps," he said,

**This name has been changed.*

pausing a beat. "You'd better get tested."

Jewish women of European descent, known as Ashkenazi Jews, are far more likely than other women to have a mutation in one of two genes, called BRCA-1 and BRCA-2 (short for Breast Cancer 1 and Breast Cancer 2), which can predispose them to breast and ovarian cancers. As an Ashkenazi Jew with ovarian cancer, my mother had a 40 percent risk of having the mutation.

Now, I'm not good with numbers, but even I could see that if I had a mutation, it would shoot my cancer risk through the roof: I'd face up to a 60 percent chance of contracting ovarian cancer, and a 15 to 85 percent chance of breast cancer. On the other hand, Narod said, if I hadn't inherited a mutation, my risk probably was no greater than if I had no family history at all.

The genetic tests are expensive—$2,400 for an examination of every bit of the BRCA genes and $450 for a narrower view of the section likely to hold a genetic error in an Ashkenazi woman. But my mother's doctor didn't mince words. "If I were you," Wallach said, "I'd have the test done this week. And if it were positive, I'd check myself into a hospital."

I thanked him, hung up the phone, and started to cry. Prophylactic oophorectomy is what Wallach was talking about—taking out my ovaries before cancer has a chance to strike. This was more than I had bargained for. At 41, in seemingly good health and with no desire to induce premature menopause, I was looking for a risk-reduction strategy, not vivisection.

But if it turns out I have the mutation, Narod said, it would be foolhardy to rely on screening. He cited a recent study in England in which 20,000 women got blood tests for seven years, with ultrasound follow-up. In the group that was screened annually, 16 women were found to have ovarian cancer. Sadly, 11 of the 16 had advanced cases.

"To me, that ain't good enough," Narod said. "I don't want to tell my patients, 'Hey, go for screening. If you get ovarian cancer, there's a five out of 16 chance we'll cure you.' You're going to say, 'Thanks but no thanks, Doc. Take out my ovaries.' I mean, if you had any brains that's what you'd say."

That got me mad, but it also got me moving. I called Tom Frank, medical director of Myriad Genetic Labs in Salt Lake City, which provides commercial BRCA testing (with a doctor's order). Once they had my blood sample, Frank said, Myriad technicians would zero in on the two suspect genes and check for any mutation.

"We proofread all the letters of the genetic code of these genes," Frank explained. "There are 17,000 letters of genetic code, and each one is individually proofread. The test has to find a single letter that's out of whack."

In my imagination, I saw row after row of little men in green-plastic visors, hunched over microscopes. I wanted those genetic bean counters on my side. I had some blood drawn at my doctor's office and sent it off.

Some weeks later, after my partner gave birth to our new son and all hell was breaking loose in our house, I got a short E-mail note from my doctor: I didn't have the mutation.

I would have thought I'd be ecstatic. Instead, after months of reliving my mother's death and investigating my own risk, I felt numb. But when I mentioned it to friends and family, they were all happy for me.

"So what are you going to do now?" one friend asked me. Meaning: Will I continue to get tested?

Hmm. The risk still felt real. My mother's death still felt fresh.

I've decided I'll go for yearly blood and ultrasound checks. But I've stepped off a runaway train of fear. When I got a stomachache last week, I knew it was from coleslaw, not cancer. I'm no longer scheming about ways to take part in clinical trials of new tests for ovarian cancer.

And now, as I watch Evann dancing and prancing through the fields near our Vermont home, I've stopped worrying about a time bomb ticking in her DNA.

Or a bomb in mine. I can concentrate on the things that matter: changing little Raphael's diapers, singing dopey songs with Evann, and doing what my mother would do—squeezing in all I can. ■

Alexis Jetter, a contributing editor, is co-editor of The Politics of Motherhood: Activist Voices From Left to Right.

Buyers' Guide

Most of the products mentioned in HEALTH magazine are sold at major drugstores and department stores. Fashion credits and harder-to-find items are listed below.

Cover

Polo Sport cream ribbed turtleneck sweater.

Healthy Looks *(page 43)*

PRETTY FAST: **Agnes B.** black sweater. **J.F. Lazartigue**, 212/288-2250. **Redken Active Express** available in salons and beauty supply stores.

PICTURE PERFECT: **Banana Republic** wine suede shirt.

SOLE SALVATION: **Rockport**, 800/762-5767. **Kenneth Cole**, www.kennethcole.com. **Living Arts**, 800/254-8464. **Merrell**, 888/637-7001 or www.merrellboot.com. **Taryn Rose**, www.TarynRose.com.

Body Work *(page 56)*

Abercrombie & Fitch white sleeveless hooded top and blue wind pants.

Fitness *(page 60)*

InSport black sport tank top with green stripes. **Danskin** black leggings. **Reebok** running shoes, 800/843-4444 or www.reebok.com.

Alternatives *(page 76)*

J. Crew blue sweater, 800/562-0258. **Margaret Thierry** light blue mohair hat, 503/325-5542. **Express** sunglasses and turtleneck.

Good-bye Middle Age, Hello New Age *(page 114)*

Renewal: A Time for You video program, 800/203-5585 or www.aswechange.com. **Ralph Lauren** taupe cashmere sweater available at Saks Fifth Avenue.

1999 Healthiest Beauty Products Awards *(page 126)*

Burt's Bees, 800/849-7112. **Dermalogica**, 800/831-5150. **Avon**, 800/367-2866. **Aveda**, 800/328-0849. **Philosophy**, 800/568-3151.

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