

Chapter 2: Warnings - My Ovaries Are Trying to Tell Me Something

Before I was discharged from the hospital my surgeon and my gynecologic oncologist had warned, “Stay off the internet. You’ll only succeed in terrifying yourself.” If their intent was to protect me by saying this they had failed miserably. Rather than sending me home armed with knowledge, they sent me home with a gaping information void, a black hole that filled up quickly with confusion and fear. There was no way I would wait until my post-surgical treatment consult to learn more.

Stay off the internet, stay off the internet, stay off the internet repeated itself over and over as I lay in bed worrying. I am a champion worrier. I worry like I’m in a worrying contest. I have spent a lifetime worrying my way into and out of life situations. So naturally, once I was feeling stronger, all I could think about was climbing the stairs to my office, getting online and searching for information to worry about. Knowing that the inside story on ovarian cancer was just a click away, and being urged to ignore it, was like having an itch I couldn’t scratch. So one quiet afternoon when Paul was out running errands, I defiantly padded my way upstairs to my office and began investigating what has become a never-ending search for information about this disease. A search that persists to this very day as research and new discoveries create an ever-shifting landscape of knowledge.

I learned that ovarian cancer was often referred to as the “Silent Killer.” (such a gentle start into my research, right?) I read that most people who develop ovarian cancer die of it: half within five years. And this figure increases to 85% after five years. I was confused, because “Silent Killer” seemed to intimate that there were no symptoms, and I had **definitely** experienced a cluster of symptoms prior to diagnosis. These symptoms had abated after surgery and treatment.

Five years later ovarian cancer's moniker changed. People began calling it "The Disease that Whispers" because it was discovered that my experience wasn't unique. Most women identify symptoms prior to diagnosis. These symptoms, while subtle, are persistent, and progressive. To make matters worse it's tricky to diagnose because the warning signs are the same as those attributed to other more innocuous conditions. That's why I like to call it "The Chameleon Cancer." Just like that sly lizard, it hides in plain sight. You can be looking right at a chameleon and not see it because it appears to be something else.

My five-year-old niece, Ella, knew how to spot a chameleon. "That's where the reptiles live," she instructed, pointing at The Herpetarium Building one afternoon when we visited Madison's Vilas Park Zoo. She was gleeful as she showed me the exotic South American frogs, shuddered as we peeked into the plexiglass enclosure where the tarantulas lurked, and she giggled uncontrollably as we studied the chameleon exhibit. "He's right there Aunt Laura! Can't you see him?" I was too embarrassed to admit that I couldn't, so I said, "Oh yeah, now I see him." She peered at me, "Okay, where is he?" Busted! I felt like a failure. "Here," she insisted. "I'll help you." She slipped her tiny hand in mine and walked me over to a picture of a chameleon. She explained, "You just make your eyes *know* what to look for. See? Just look at the picture. Okay. Now that you *know* how long he is, and you *know* that he has huge weird bulging eyes all you have to do is concentrate and you'll see him." We returned to the display and I saw him. I don't know who felt more triumphant, me or my young teacher.

My cancer hid in plain sight for a year looking like acid reflux, or an overactive bladder, or peri-menopause. That's because the subtle warning signs of ovarian cancer are the same as the ones associated with these more common conditions. This is further complicated by the fact that doctors spend a scant few hours learning how to differentiate ovarian cancer between several conditions that share similar signs or symptoms. After misdiagnosing the disease, and applying one size fits all treatments for garden-variety

conditions proves ineffective, physicians will sometimes grasp at straws as they search in vain for an explanation. One survivor I met was told she had swallowed a sea creature, another was admitted to a psych unit and given electroshock therapy after being diagnosed as mentally ill.

Accurate diagnosis is further hampered by the fact that traditionally, as women we aren't taught the warning signs of this dangerous, prolific killer. We don't *know* - what we don't *know* - so *we* can't see it. Several months before I was diagnosed, *Prevention Magazine* had a short sidebar article about the CA125 screening test and ovarian cancer detection. When the subject came up over coffee with girlfriends, we spent barely a nanosecond on it. I recall saying, "Ovarian cancer. Isn't that the disease that Gilda died of? You know, the one that nobody ever gets?"

"I get my pap smear every year," said Pat, "And it always comes back normal." We all nodded, smug fools that we were, collectively believing we were being screened for any life threatening diseases during our annual check-ups. Most women don't know that there is no accurate medical test for early detection. In addition they have no idea that regular screening questions are not a part of our medical practitioners' protocols. My girlfriends and I dismissed the subject and moved on to more pressing topics like; 'Biscotti-why does it always taste like stale bread?' I had no idea that my survival would depend on *me knowing* the warning signs and then communicating any concerns to my doctor.

Compounding this ignorance is the fact that the Internet has enabled us all to become our own amateur physicians and specialists. This brilliant research tool can be something of a double-edged sword. On the one hand it can be empowering beyond belief, enabling us to become well-informed medical consumers and active participants in our overall health care. On the other, it can be the perfect example of the adage, '*A little knowledge is a dangerous thing.*'

I have lost track of the number of times I've visited WebMD and clicked my way through a symptom checklist in order to diagnose myself or, God help them, someone else. Prior to my diagnosis I had expertly researched my symptoms through several internet surfing sessions. I - the great Dr. Clark Hansen - wrote my red flag-ovarian cancer symptoms off to peri-menopause, the condition du jour.

Every one of my coffee klatch girlfriends, and all of my sisters were talking about the emotional and physical issues we were experiencing as we tiptoed up to the edge of what our grandmothers had called, "The change". After reflecting on the old wives' tales that we learned at my grandmother's feet, I felt certain my assessment of the situation was correct.

Grandma Clark began our indoctrination into the wonderful world of womanhood early. Lined up like sparrows on a picket fence, my sisters and I perched on the edge of her living room couch, mesmerized. As she squinted through the smoke curling into her eyes from the Benson and Hedges 100 cigarette dangling dangerously from her lips, she fixed each of us with a take-no-prisoners glare. "When you become a lady you'll suffer the curse every



month." She paused to tap the cigarette's growing ash into the tiny 1904 World's Fair commemorative ashtray she had purchased at a junk store near the family farm. "When I was a girl we would take old flour sacks. Then we'd fold them over and over and pin them to the inside of our bloomers. Becoming a woman is a filthy mess."

Sitting at her vanity in front of a three-way mirror, grooming her hair with a comb soaked in beer and Dippity-Do, she corkscrewed the wispy strands of hair in nests and secured them to her head with crisscrossed bobby pins. She continued to inform us about

the horrors of childbirth. “A few seconds of sexual satisfaction and for what? Nine months and eighteen years of hell!” Sipping a cup of tea as she prepared for bed, basking in the afterglow of a wonderful episode of that western series *Gunsmoke*, she reflected on the saloon keeper Miss Kitty’s status. “Oh she might be beautiful all torted-up like that today, but one day she’ll go through “The Change.” Oh sure, you will too. Your blood stops flowing, like shutting off a tap. Then you’ll all look just like me.” Mercifully we were still too young to realize what a horrifying thought that was.

The wisdom learned at Grandma’s knee combined with internet acquired knowledge encouraged me to ignore my oh-so-vague ovarian cancer warning signs. There *are* classic symptoms associated with this disease. I embodied, each and every one of them. I’m not the exception either; in fact, I’m the rule.

Research conducted by Dr. Barbara Goff of the University of Washington, Seattle indicates that eighty five percent of the ovarian cancer patients she studied experienced one of the common symptoms prior to diagnosis. She also discovered that ovarian cancer patients were much more likely (from two to thirty times more likely) to visit their doctors to discuss one of the common symptoms in the year prior to diagnosis. So before we dot another I, or cross another T, let’s talk about the most common symptoms. Any significant changes that are a departure from your “normal” should be discussed with your health care provider, especially if these changes are persistent and progressive.

Through most of my adult life my menstrual cycle had been as regular as a metronome. You couldn’t set your watch by it, but you could probably track the moon. Twelve months prior to my diagnosis, things changed - abruptly. My menstrual cycle became irregular and unpredictable. I guess Granny didn’t know that unexplained irregular periods could be a sign of a gynecologic cancer or that menstrual changes should always be discussed with your health care professional. I learned later that this condition, which I attributed to the beginning of menopause, is something that is referred to as dysfunctional uterine bleeding.

I also began getting fluffy around the middle, which is just a nice way of saying I was getting fat. My stomach, while never flat or taut, had begun to plump out dramatically. I launched a full-on frontal assault to address this attack on my belly by rejoining Weight Watchers. This time it was grueling in a way that it hadn't been in the past. Taking off the weight was like chiseling cement. Though the scale inched down ounce-by-frustrating-ounce, my stomach continued to expand. I attributed this body change to the unfortunate way my family aged. My aunts, my mother, and heaven knows, both of my grandmothers were girdled and corseted within an inch of their lives to contain their girth. *Unexplained weight gain or weight loss are both symptoms associated with ovarian cancer, as is a swelling of the abdomen.*

Then there was the gas. Oh dear God, the gas. At the time, my husband and I were traveling throughout the Midwest conducting trainings with young people, helping them develop skits about teen issues. By early afternoon I was often experiencing a bit of abdominal distress, bloating, burping, and farting. I'd spend the better part of the afternoon teaching with my pants unzipped, butt cheeks clenched like a lock wrench. By the end of the day I would be jet-propelled out of the classroom.

One evening as I lay on my hotel bed in the breaking wind pose I'd learned in yoga I timed the outbursts. There was never more than a five-minute hiatus between explosions. Yet I never even thought about mentioning this to my doctor. It never occurred to me that this was dangerously abnormal.

Excess gas can be a warning sign of ovarian cancer. Let's be clear about what excess gas is. Excess gas might be indicated if you need to unzip your pants because your belly swells up. It could also feel like a pain in your tummy. Or you might just find yourself farting or burping uncontrollably. That's excess gas. Let's face it, these aren't topics for polite conversation. So I never discussed them with anyone. I wrote it all off: to the high fiber diet I was consuming; to my age; to my stress level; to peri-menopause. It never occurred to me to consult a health care professional to discuss this persistent and

distressing symptom.

As we began the 2005 school year a couple of new nagging issues began to concern me. When I was speaking or teaching I would sometimes run out of breath before the end of my sentences. I'm a professional actress. I had been singing and tap dancing my way through life up until the time we formed our own production company. Believe me, belting out a song while you're doing a time step takes a lot of air, and yet all of a sudden I didn't have the lung capacity to speak. I felt winded just walking up a flight of stairs. And I couldn't seem to take a deep satisfying breath. *Shortness of breath, for example running out of breath when speaking, or the inability to sigh deeply, can be some of the warning signs of ovarian cancer.*

I had stopped drinking water during the day when I was conducting seminars, because if I did, I found myself racing to the ladies room all day long. After announcing a five-minute break, I would make a bee-line for the bathroom, tripping over students on my way, impelled by an overwhelming urge to pee. *Urinary symptoms such as an increase in frequency, or urgency are warning signs associated with ovarian cancer.*

Then something really weird happened. Early one evening after returning from an exhausting day working with a group of rowdy middle school children, I noticed something new. As I sat perched on the edge of my hotel bed retrieving voice mail messages, with my pants unzipped and farting like a motorboat, I became keenly aware of what felt like a toad squatting in my uterus.

"Honey." I said softly to my husband, who was reclining on the queen sized bed opposite mine, "I think I need to see a doctor."

"What's wrong?" he inquired, more curious than worried.

"I have a toad squatting in my uterus." I announced.

He looked at me with a quizzical furrowed brow, his question – 'Huh?' - drifting unspoken in the air.

"It feels like a toad... it feels like a..." I squirmed trying to feel for a way to

describe it, searching for an image. I held my hand up in front of my face, and clenched it. “I don’t know. It feels like a toad that’s just about the size of my fist.”

The atmosphere in the room changed in that moment. Even now it stands out as a seismic shift. The air was charged with an, *I’m-Sure-It’s-Nothing-But-I’m-Really-Freaked-Out*, kind of energy. The chameleon had finally revealed itself. The relentless whispers had become as loud as a banshee’s wail. I dialed my internist and made an appointment for the day after Thanksgiving, a week away. *Pressure or a feeling of fullness in the abdominal or pelvic region can also be a warning sign of ovarian cancer.*

I teetered back and forth on the decision to abandon our carefully arranged holiday plans. I didn’t want to spend precious vacation time with my legs dangling over the edge of an examination table when I felt they should be firmly tucked under the holiday table of one of my sisters. Ultimately my husband prevailed saying, “If it were me we were worried about, there would be no discussion. You’d *make* me go.” Well, he had me there.

So we moved forward in diagnosing my mystery symptoms. My family practitioner at the time wasn’t a gynecologist or a top-notch Internet MD like me. She was a family doctor who asked questions, listened to the answers, and conducted careful, thorough physical exams. More importantly, she was tuned in to the current information about the warning signs of ovarian cancer. She was on high alert as soon as she finished the physical exam and snapped off her gloves. She quizzed me about every possible gynecologic cancer symptom. We both agreed that something was just not right. Without hesitation examinations were quickly scheduled, and tests were performed. A transvaginal ultrasound, a CA125 blood test, and another more extensive pelvic exam with a gynecologist were completed in short order.

The CA125 test was easy and painless. It involved walking across the hall to the lab where the phlebotomist drew blood. A lab technician then ran a test to quantify the presence of the CA 125 protein enzyme. This particular enzyme is often elevated when ovarian cancer is present. Mine was 58 - normal is 0-35. Many women with ovarian

cancer have numbers that reach well into the hundreds and even the thousands, but some have numbers that are almost normal. My brand new gynecologist informed me that this low number probably indicated cysts, or fibroids.

The transvaginal ultrasound was next in line on the hit parade of screening tools. Never having been pregnant I had no idea what a treat I was in for! In order to prepare for this procedure, I was instructed to drink two quarts of fluid. Unfortunately, nobody explained that the beverages should not be carbonated, or that I couldn't pee until the blessed event was concluded. I waddled around the waiting room trying to distract myself by repeating the names of all fifty states in alphabetical order, first forward and then backward. I was up to South Dakota when my name was called. I penguin-walked toward the procedure room, taking mincing steps and praying my stressed-out bladder would hold.

A nice young man explained that we would need to wait for a female staff member to join us since this was a rather intimate test. 'What the hell is he talking about?' I wondered. 'I have to pee.' Then one of the perky receptionists I had met at the front desk poked her head inside the door and after a timid knock asked, "Do you mind if I just finish my lunch? I was on break when they paged me."

I said, *"Sweetie, would you mind eating your lunch while we do this? I'm about to projectile pee all over this nice young man."*

After her embarrassment subsided she made herself comfortable on a stool in the corner with her Doritos and her can of Fresca while the nice young man explained the procedure. I sat quietly wondering if maybe he was joking. Dr. Clark Hansen WebMD was woefully ignorant about the whole transvaginal procedure. *With my jaw dropped to the ground like a cartoon character, I remembered a scene from Alien and asked* "Seriously you're going to insert that foot-long probe into my vagina and then press down on my very full bladder with that hand thingy?"

He nodded, clearly unable to reassure me of how the female anatomy accommodated this invasion. I turned and looked at the receptionist for confirmation. She nodded with a more compassionate look. It was surreal. They looked like a couple of bobble head dolls. This felt more like an alien abduction story than a bona fide medical procedure. But who was I to argue? I was just a WebMD. “Well okay.” I took a shallow breath. “Let’s run it up the flagpole and see who salutes.”

A week passed. Time had never crawled along at a more glacial pace. And then the phone call came; the one we all dread. My vigilant doctor used words like: cysts, and masses, and neoplasms. My heart throbbed in my chest, the toad in my pelvis pulsed and oozed, and time floated into slow motion. But the medical procedures continued to move forward at breakneck speed.

I was informed that, thanks to the holiday season, elective surgeries were on peoples’ back burners. The doctor’s schedules had wiggle room. What stroke of luck! I imagined empty waiting rooms with bored receptionists who could take two-hour breaks without having to eat lunch staring into some random person’s vajayjay. I envisioned empty operating theaters – vast gleaming wastelands - with shining trays of sterilized instruments - and no patients to cut or clamp.

Before I had time to fully grasp what was happening I had slipped through the surgical system like a skipping stone, set aloft on the hope of a deceptively low CA125. But when I awoke from surgery, ten days after my initial appointment, my buoyant attitude sank. My surgeon’s face swam into view as I woke from my twilight sleep and I uttered a word that shouldn’t be repeated in polite company, but most accurately conveyed my feelings. “Shit.” I whispered.

“You know, don’t you?” I could tell she was terribly sad. She leaned on the railing of the gurney and touched my hand, “How do you know?” Maybe she expected to hear a strange story about how I had astral-projected out of my body and hovered below the ceiling during the operation. Maybe she thought I’d seen them remove the swollen

grotesque masses my almond shaped ovaries had become. Maybe she thought I learned the news that way, however, the truth was nothing quite so exotic.

“You said you wouldn’t see me until I had my staples removed.” I groaned, “So something must be wrong.” We locked eyes. She inhaled. Eternity lived in that moment, hanging suspended on the breath of hope. She exhaled saying, “You have ovarian cancer.” She continued to talk. I watched her mouth move as she said something about a gynecologic oncologist who was called in to complete my surgery when they discovered that my tumors weren’t benign. She said something about how a woman’s chance of survival increases dramatically if she is operated on, and debulked, (that means cleaned out) by a gynecologic oncologist. She said a lot of things before taking her leave. She talked about ovaries swollen to the size of peaches or pears, implants as round as freshly grown peas, and pomegranates bursting with tiny black seeds. The fruit and vegetable analogies seemed endless. I tried to remain present to absorb this life altering information, but all I could think about was my husband, Paul, alone in the waiting room hearing this same news in isolated agony. And I longed to hold his hand.

Instead I found myself clenching the sides of my bedding, holding on for dear life, as I was transported to my hospital room. The gurney thumped along on its tiny wheels; singing grrrrr grrrrr bump, grrrrr grrrrr bump as I was slalomed through the halls. I stared at the ceiling, one tile, second tile followed by a glaring light... tile, tile followed by glaring light. Then, as we rounded a corner, I heard Paul’s voice somewhere near. I called for him, or I thought I did. My words were like tiny puffs of air. I felt like I was in a nightmare and was unable to create sound when I needed to most. I could only expel exhalations of whispered desperation.

“Paul, Paul, Paul, Paul.”

A voice sliced through my hushed cries. “On my count; one/two/three.”

Gently, they lifted me up, sheet and all, and shimmied me into my hospital bed. Tubes were adjusted, instructions about morphine pumps were dispensed, and

reassurances were given. Then as the sea of scrubs parted, Paul slipped through the opening and folded my hand in his.

“I’m sorry, honey. I’m sorry. I’m so sorry. I’m sorry.” I repeated over and over and over and over and over. Our ovarian cancer journey had begun.