

## The Inheritance

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In a cookie-cutter west-end home with coral brick facade and spotless white wall-to-wall carpets, a young mother named Karen Knapp waits for the phone to ring. The very essence of womanhood, with her long blond hair knotted high on her head, she breast-feeds her eight-week-old daughter, then bathes her two-year-old, also a girl, all the while listening: anticipating an answer to a question she's been asking since she herself was a child.

As virtually every woman in her family has fallen ill from breast cancer, she has wondered, not so much if she'd get sick and die, but when it would happen; whether something inherited means her body is destined to betray her; whether, in fact, she has the breast cancer gene.

Now, the answer is near.

Yet when the phone does ring, she lets the answering machine take over. Four, five, six times a day for a five-week stretch, she refuses to answer the phone. She says she doesn't want to be caught off guard. When she hears the message, she will return it, calm, composed and in control.

Her husband, a doctor, whose calls to check on their girls go unanswered, thinks she's being silly. But then, Don Knapp confides that he doesn't think she should have had the test in the first place.

One day, after weeks of waiting for the call, Karen can no longer take it and phones the hospital. The line is busy. When she puts down the receiver, her phone rings. Startled, she picks it up. It's the hospital. They want to see her. She can't believe the one call she answers in five weeks is the one she has been waiting for.

Is this a good or bad sign? She decides it is destiny.

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Just after dawn on the day Karen is scheduled to get the results, Don carries their baby girl into the master bedroom and lays her beside his wife, who produces her near-bursting breast.

"How are you feeling?" he asks.

"I feel nothing. After all this waiting. Nothing," she says.

Later, when husband and wife and newborn are strapped in their minivan, he asks again.

"I'm sure I don't have it," she says. "My mother has been going to church every day praying for me. Besides, my mother has had it, my aunt had it, my cousin has it. Everyone else has had it. The chances are I can't possibly have it. I don't have the breast cancer gene."

Her husband, a chronic care doctor and a pragmatist who frequently deals with life and death, worries that she's not prepared for bad news. "But what if you do?" he prods. "Don't you think we should prepare ourselves for that?"

Karen confesses that she worries a positive result will end their plans for a large family. She also worries about her breasts. If it's positive, should she consider a double mastectomy? She doesn't tell him she thinks she might die.

Don thinks about what to say. "If we can't have more kids, we can adopt."

Karen smiles.

“And if you have to get your breasts cut off,” he continues, “look on the bright side, you can get a nice new pair. You can pick out the kind you always wanted. It’s a win/win situation.”

Before the words are fully out of his mouth, he knows his attempt at lightness has backfired. She fails to laugh. They fall silent.

The technology that promised a window into Karen’s future and a chance, perhaps, to save her life, has brought unprecedented loneliness. Her relatives -- mother, aunts, cousins -- fear she is unearthing dangerous information, and perhaps black-listing the entire family from future insurance and employment. She is alienated from her well-meaning yet clumsy husband, who doesn’t understand why she needs to know if she carries a mutant gene that very probably will make her sick. She feels utterly alone.

As they near the hospital Karen looks back at her baby girl bundled into the car seat and reminds herself why she wants to know her future.

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When Karen first met Don she told him she wanted seven children. He only wanted three. They settled on four.

She wasn’t sure why a large family was so important to her. Growing up, she only had one brother, and envied friends who came from noisy, boisterous households filled with brothers and sisters who were playmates and confidantes. Or maybe she felt there was strength in numbers, that the cancer that stalked her family couldn’t possibly get all her children.

Weeks before Karen even took the test, before the morning when she and her husband drove nervously toward destiny, she sat in the living room of her home, cradling her newborn daughter, while her two-year-old played noisily and reluctantly on the carpet. “Mommy, me. Me,” the toddler insisted, trying to tear her mother away. But Karen wanted to discuss the women in her family, the illness that stalks them, and her need to know if it will get her, and one day, her girls.

On the dark oak buffet in Karen’s home, pictures of three generations of women, some wearing the formless, dark dresses of an earlier time, are encased in ornate frames that could easily be tombs. Karen’s great-grandmother died when she was 64 following a brief fight with breast cancer. Her grandmother was butchered by a country doctor who lopped off a diseased breast and then sent her home to die. She was 48. Her aunt, who developed it when she was 48, fought valiantly as the cancer spread from breast to brain until she slipped away at age 54. Now, her 56-year-old mother has the disease, and a 41-year-old cousin is battling it.

“When I first became pregnant three years ago, I prayed it was a boy,” says Karen, who is 30. A boy, she reasoned, would escape the poison that had passed from grandmother to mother to daughter as if it were blue eyes or blond hair or good looks.

Her prayers were not answered. In March 1997, she gave birth to her first girl. This was, after all, a family of women. “I’d look at her and wonder if I’d doomed my girl to the fate of my ancestors.”

A year after Samantha was born and a few weeks after Karen stopped breast-feeding, she found a lump in her still engorged breasts. She pinched at it, then fondled it, then madly scrubbed it, but it would not go away. Then she stopped touching it altogether. She greeted the find, not with shock, but resignation. If anything, she wondered why it had taken so long to worm its way from phantom to fact. She didn’t tell her husband, whose skilled physician’s hands might have explored the lump or at least comforted her. Nor did she tell her mother, who two years earlier had lost her right breast.

When Karen finally sought diagnosis, a surgeon told her the lump was benign. However, he did not offer relief. When he heard Karen’s family history he suggested she seek genetic screening. The next lump could be life threatening, he told her. Screening would tell her if her family’s cancer was genetic, and perhaps, she, unlike the women before her, could do something to thwart the disease. The surgeon also told her that maybe luck was on her side. Maybe she hadn’t inherited the gene.

“I had no idea there was a test that would let me look into my future. And it never really occurred to me that I might not become sick, that I might escape.”

More than three years earlier, in October 1994, at the annual conference of the American Society of Human Genetics in Montreal, a team of geneticists announced they’d found BRCA-1, located along chromosome 13. BRCA-2 was found a short time later. Mutations in either gene were thought to be responsible for most forms of hereditary cancer. Within two years of that discovery, a test was available.

Predictions of the test's impact were often dire and dramatic. The Toronto Hospital's Dr. Gordon Mills, who was then helping locate the genetic mutations, told the Citizen: "I will bet by the year 2000 every woman by the age 20 will head to the lab for her test for the breast cancer gene." A top Ottawa cancer surgeon wondered, somewhat callously: "What are their lives going to be like when we tell them they have the gene for cancer? Are more people going to be jumping out of windows?"

"We've got to be careful that we don't destroy the joy and the optimism that is the basis of living life fully," said well-known McGill University ethicist Margaret Somerville. Breast cancer survivor Sharon Batt echoed what many activists would come to feel: "What's the point in giving a death sentence when there's not much people can do for women with this gene?"

While the technology rushed ahead, psychologists wondered what the impact would be on women and their families as this test invaded their lives.

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Sitting in her living room, Karen recalls leaving the surgeon's office that day, shaken, but oddly hopeful about the potential power of the test. She wanted to wake up each morning, as she assumed most other young women did, without fretting about lumps, mysterious masses or strangely dense tissue. She also wanted to have more children. She wanted to see them grow up; to attend their high school graduations and weddings; to see them grow into women and men; and one day she wanted to become a grandmother. She felt that if this testing might somehow prolong her life, by giving her access to treatment earlier, it was worth pursuing. It was with these desires that she made an appointment with a genetic counsellor at the Children's Hospital of Eastern Ontario.

Some days, after her day is done, Cathy Gilpin closes her office door in the basement of CHEO, puts her head in her hands, and cries. It's usually after she has told a young woman that yes, she does have the breast cancer gene, and the woman has left her office to go home and cope with the news. "I feel like somehow it's me that's ruined their lives," she says, sitting in the cramped office where she usually delivers the news.

Cathy was hired straight out of McGill University, where she'd received a masters degree in the relatively new field of genetic counselling. Her task was to set up the breast cancer counselling program at CHEO. It was an odd career choice for a woman whose family had been plagued by the illness.

Some relatives actually died of the "dreaded C-word" and were never mentioned again; the subject was so taboo. After her grandmother died of the disease, Cathy didn't talk to another patient until her training at the Sunnybrook Medical Centre in Toronto. "I was filled with fears from my family experience, I was scared to death, close to tears. I thought I was going to see a monster or something," she recalls of the prospect of meeting her first breast cancer patient. The oncologist had to lead her by the arm into the hospital room. "I quickly realized that I would meet the nicest women in the world."

Since 1997, Cathy has counselled more than 400 women who either have cancer and want to be tested to provide the information for other women in their family, or who come from families where cancer strikes frequently, and often, at a young age. Almost 200 women have been tested; 35 have tested positive for the breast cancer gene.

When Karen came into her office in May 1997, clutching her year-old daughter, Cathy felt an immediate affinity for her. Not only were they the same age, she recognized Karen's intelligence, curiosity and courage. The first member of any family who comes in to discuss genetic screening has an incredibly difficult job. They are the ones willing to confront the unknown. They are also the ones who want to try to change the course of the disease.

Karen was extremely nervous. She hadn't told anyone about the appointment, not even her husband. She felt like she was on a solitary journey to uncover her fate, and by extension, her baby daughter's. Cathy, a freckle-faced redhead with a calm, reassuring manner, listened to her fears.

Together in the cramped office, around the small table, Cathy and Karen built Karen's family tree. Not just anyone can be tested for the BRCA mutations. A woman who was tested usually must have a mother or sister under 50, or two relatives under 35, with the disease.

"It's full, absolutely full," Karen whispered as the paper in front of her filled up with the names of women in her family who had died of cancer.

This couldn't be a family tree built on myth and misinformation. Karen would have to get all the diagnoses confirmed and get release forms signed for her aunt's, mother's and cousin's medical records. It also meant she couldn't keep her quest quiet, a fact that Karen would have to wrestle with. Although she knew she needed support, she didn't want to tell too

many people because she realized once people learned that she had the gene, she would be forever marked. "That's information you can't change. It has to be carefully guarded."

If Karen decided to give a blood sample, it would be screened for inherited mutations in both BRCA-1 and BRCA-2. We all have these genes, but some women who have breast cancer, or who come from families with a high incidence of breast cancer, have alterations or abnormalities in these two genes.

"A gene is like a set of instructions," Cathy told Karen. "If there is a spelling mistake in these instructions, the orders it gives won't be carried out, or they won't be carried out properly."

The BRCA genes, when working properly, are tumour-suppressor genes, a type of brake pedal for our cells. Through the proteins they make, they tell our cells how fast they should divide and when to stop dividing. If there is a spelling error -- or mutation -- in these two genes, cells grow and multiply faster, they live longer than they should, and cancers develop.

Cathy explained that scientists believe that defects found in one or both of these genes are responsible for nearly 10 per cent of the approximately 19,300 cases of breast cancer diagnosed in Canada last year. In general, a woman has a 10-per-cent chance of developing breast cancer by the age of 85. These odds can rise to more than 80 per cent -- depending on age and family history -- among women who have BRCA mutations. Ovarian cancer is much less common. A woman has only a 1.4-per-cent chance of getting it by 85. Women who carry the BRCA mutations have a 40 per cent chance of developing ovarian cancer.

It's not Cathy's job to encourage testing, or give advice, she only lays out the options. "You don't have to be tested," Cathy told Karen. Instead, Cathy offered to set up an aggressive screening program -- with frequent mammograms and ultrasounds of her ovaries, as well as vigilant self examinations -- similar to those designed for those who actually carry the genetic mutation.

Cathy told Karen it was vitally important that she knew what actions she would take in the event of a positive test, which would mean more than an 80-per-cent chance of developing breast cancer.

Karen realized that there would be no point in taking the test if she would not act on the information. That weighed heavily on her. Cathy told her many high-risk women take Tamoxifen and Raloxifene to try to prevent cancer growth. The chemo prevention is considered 50-per-cent effective in preventing the appearance of cancer; however, there is the potential for serious side effects. Tamoxifen, for example, may increase a woman's risk of uterine cancer.

Continued on Part 2

## **Geordi 'was here for a reason'; Amanda George learned her son's wishes by watching his eyes, writes Shelley Page**

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There were "12 truths" about Geordi Henry. His mom posted them above his bed, so no matter who encountered him lying there, they would understand that he was much more than the sum of his rigid limbs, gurgles and squeals, and dancing eyes. Instead, they might glimpse his heart.

Amanda George begins to recite:

"Use rainy days to rest your body and your mind.

"Older sisters are great. "The sounds of plastic crinkling and birds singing put a smile on your face."

She pauses and falters, unable to remember the rest. The framed list is at the funeral home. She looks down at her empty hands limp in her lap, which prompts her to recall another: "Being held is one of life's greatest comforts."

A flood of sadness comes.

This list was drawn up when Geordi was five and no one was sure how long he would live, or what kind of mark he would make in his difficult life.

"He was here for a reason. He had a lot to teach and there were many people willing to listen," George says.

"You wouldn't think, to look at him, but he touched people," adds his nurse, Ann Parizeau, who cared for him for a decade.

Geordi died Jan. 30, at age 17, from complications due to pneumonia. He was a child of his community. The charity OneBoyOneVan - started by George - has helped nine families purchase vans for their wheelchair-depend-ent children. Because of Geordi, galas, bake and books sales have been held. Four other families await funds for a van.

The first time the Citizen wrote about Geordi was to tell of the launch of OneBoyOneVan and its first recipient: Geordi.

It was October 2007, and winter was approaching. In an interview, George said she was extremely anxious about how she would get her unbendable, breakable boy from their Beacon Hill apartment to his appointments.

Geordi, then 12, was born with severe cerebral palsy, scoliosis, microcephaly - an abnormally small skull - and a seizure disorder. Because his muscles were tighter than violin strings and his hips were dislocated, he did not bend.

To accommodate his board-stiff body, a year earlier Geordi had received a wheelchair that always re-mained reclined. But it was five feet long and wouldn't fit in a car, if George had one, which she did not.

When the family (Geordi had an older sister) went out, George borrowed her mother's car and left the wheelchair at home. She then put a parachute-like harness on her son, carried him through the snow, then slid his 47-pounds into the back seat, attached his harness to the seat belts, cushioning his head and feet with pillows.

She said she worried constantly that she'd drop her son. As she spoke, he looked at her with deep concern in his dark eyes.

George learned her son's wishes by watching his eyes, where they looked, how they darkened or smiled, narrowed or shimmered. She knew he was scared, too, when she'd stumble along icy walks carrying the full weight of him.

When she promised to get her son a van she knew it was a pipe dream. The van was \$65,000. The family was broke. Her two part-time jobs at the Children's Hospital of Eastern Ontario barely covered the bills.

So George did something out of character: she went public. The single mom's needs were summed up in the name of the website she had just created to solicit help: [www.oneboyonevan.com](http://www.oneboyonevan.com).

She had one boy, and he needed a van.

By the time the Citizen wrote about her quest, she'd already raised \$38,955 through garage sales, support from the Max Keeping Foundation, the President's Choice Children's Charity, the Ontario March of Dimes, and from Bubblegum Days at Thomas D'Arcy McGee Catholic School, where Geordi attended school with other severely disabled children.

Within two weeks, almost \$15,000 had been donated. A fundraising gala had sold out, raising another \$12,000.

When all the money was counted, George could purchase the van, but also insurance and the DVD player so that Geordi could watch movies on the road - an unimaginable luxury for a boy who asks for nothing. George continued to raise money for other families with wheelchair-dependent children. Each gets \$2,000 toward the purchase of a van. Convent Glen Catholic School in Gloucester, in particular, continues to hold fundraisers for OneBoyOneVan.

The van made a significant difference in Geordi's life. Instead of lying down in the back seat of a car, he could look out the window. And for a long time after that, life was good.

Then 18 months ago, Geordi developed pneumonia and it changed everything.

He had to wear a Bi-PAP ventilator to help him breathe. This meant he was under constant watch to ensure he didn't vomit behind the face mask.

His already very small world shrunk further. He stopped going to school, and was cared for at home, with frequent respites at Roger's House. His bed was rolled into the living room, which became the hub of his existence.

In August, Make A Wish Foundation granted him a wish. We often hear of children meeting celebrities or travelling to amusement parks or taking exotic vacations. But for a boy whose world was contained in the living room, George asked for "something with lights because Geordi loved looking at lights," a Kobo reader because he loved being read to, and help hooking her computer up to her TV so they could watch movies on a bigger screen.

When the six-person design team showed up from IKEA, George knew her son was getting much more than she'd asked for. New curtains were hemmed and hung, a headboard was covered. The team worked all day assembling an entertainment unit, an elbow shaped couch, a coffee table, lamps, and nightstands. They framed pictures that had gone unframed, including the "Twelve Truths of Geordi."

On the day of the "reveal," George recalls picking Geordi up late and how "angry and cranky and fussy" he was. He wouldn't kiss her. When he got home to see the room, he refused to smile. "It took him a good day and a half to really look around and appreciate the room - and start giving me kisses again."

"It was so much more than I ever expected."

But they didn't have long to enjoy the gifts. Two months later, in November, Geordi developed an aspiration pneumonia. "Things deteriorated after that."

He was vomiting frequently and his weight dropped. Then, two weeks ago, his level of awareness decreased. He slept more than he was awake. When his eyes were open, he wasn't really there. George looked into her son's once dancing eyes, suddenly still, and knew he was dying.

Near the end, he coughed incessantly, but couldn't catch his breath. George crawled into bed with Geordi and held him tightly, one of life's greatest comforts until the end.

## **'All kinds of women get breast cancer'; For the first time in her career, Kathleen Petty, the CBC's consummate interviewer, took a step back and focused on herself, writes Shelley Page**

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Ace interviewer Kathleen Petty remembers in slow motion the moments when everything changed for her. She was in the shower - as these calamities often play out - taking a pause from the upheaval in her life.

She had sold her house; was staying with two women she'd befriended at a local dog park; and was days away from saying her final farewell to listeners. She would soon leave Ottawa for Calgary after five years as host of two CBC Radio shows, the top-rated Metro Morning and The House.

"And I looked down and my right breast looked different, really different, than my left breast. I thought, 'How long has it been like that? How could I not notice?' And I had this sinking feeling."

She got dressed and, on autopilot, drove to her doctor's office. Told her physician wasn't free, she begged to see any available doctor.

That doctor examined her breasts, and her abdomen. All felt abnormal to the touch. Multiple tests were ordered. And in the days that followed, Petty was forced to redraw her plans. She only told listeners that she was dealing with a "health issue" and that she would be remaining in Ottawa to deal with it.

She'd said: "I didn't want it to be a pity party for Petty."

Then, for the first time in her career, she took a step back and focused on herself.

During her years in Ottawa, Petty clocked 14-hour days that began at 3: 30 a.m. Outside of the radio studio, she lived a "hermit-like existence" and only left her "cave" to walk her German shepherd, Greta. She was so busy, so tired, she rarely took time for herself, whether it was cocktails with colleagues or a routine medical exam.

This drive, and her incisive mind, led to many career successes, most as host and interviewer, including as an early face of CBC's Newsworld. Last year, she'd decided to return to her hometown to host Calgary's top-rated morning radio show, and care for her elderly and ailing father.

On a recent sunny Tuesday, Petty, 50, answers the door of her friends' home, where she is still staying. Greta follows her to the door, with her roommates' dog Nugget close behind.

Petty wears sweat pants and a sweat shirt. Her head is covered in a bandana, where underneath her hair has started to grow back. She wears no makeup.

"It's not going to fool anybody," she says.

Just days ago, she had a double mastectomy. She feels pain at the incision sites and is bothered by a buildup of fluid.

She is only comfortable when she holds her arms in the air, which is, of course, impractical.

After preparing cappuccino, she sits at the dining room table, cluttered with a few recent purchases from The Shopping Channel, including reading glasses in five different styles.

The political junkie confesses that with so much time on her hands, she has added the talk show Ellen and singing shows like The Voice and American Idol to her regular daily doses of CPAC and CBC's Power and Politics.

At first, Petty says, she wasn't keen on giving interviews about her situation. "All kinds of women get breast cancer. I don't want to hold myself out as something exceptional. Sadly, it's so normal. I don't want it to be self-indulgent."

But she now thinks it's OK to "give voice" to a common experience.

She speaks matter-of-factly about all that has happened since those moments in the shower last August.

The tests revealed Petty had a large mass in her right breast that was 10 centimetres in size. There were also multiple growths on her ovaries, suggestive of ovarian cancer.

Doctors asked her how she could not have noticed these changes. She frankly isn't sure.

Then 49, she was waiting to have a mammogram when she turned 50. As it turns out, she was diagnosed with lobular breast cancer, which she has been told is more difficult to detect with a mammogram. So she's not sure it would have been detected even if she'd had one.

As for the swelling in her abdomen, "I thought it was from chips and muffins."

Chemotherapy was needed to shrink the breast tumour. But first, a total hysterectomy was ordered to determine what was on her ovaries.

It wasn't cancer. "I was producing fibroids like a factory," she said.

In early January, after several rounds of chemo, an MRI showed the breast tumour had shrunk by almost half. Several more rounds were scheduled, and surgery was booked to remove both breasts, and several lymph nodes.

Petty says she opted for a double mastectomy because "what am I going to do with one breast?"

Joking, she adds, "And if I was going to have reconstruction, why would you want to match an old breast? Could I have another ugly one over here please?" She is trying to stay hopeful, but admits she may still be in shock.

"Most people comment on how strong I've been. I'm not entirely sure that I've processed it even now. I try to deal with what I know and not worry about what I don't know or can't predict."

Oncologists have told her they anticipate a positive prognosis.

But Petty is also a realist. "They don't know and I don't know, but I will do everything they tell me to do to increase my odds. But I am not banking on anything."

Five weeks of daily radiation begins April 10.

With a lot of time to think, she tries to not second-guess her failure to notice changes earlier.

"What is done is done and I have to deal with what it is."

In her career, Petty has interviewed thousands of people. An interview with a politician has gone well when she gets "unexpected honesty" from them. For normal folk, she loves finding out information her briefing notes hadn't included.

If she were interviewing herself about her cancer, what would she ask? She pauses before posing the question.

"I would ask, 'What is the most difficult part of this?'"

And then she answers: "It's not knowing what the outcome is going to be. I'm trying to manage that swing back and forth between pessimism and optimism, so I try to stay somewhere in the middle. But I find myself not willing to get too optimistic because I know the statistics."

When will she feel she's in the clear?

"The timeline is usually five years," she says.

Her oncologist has told her she can return to work in August. CBC Calgary is holding her job.

So sometime this summer Petty hopes to load Greta into her car and head for Calgary.

This time, it will be harder to leave than if she'd left last August.

Not only has cancer made her more empathetic, and more aware of the hardships of others, it has also enriched her relationships with colleagues, friends and listeners.

Says Petty, "Cancer has given me the time to spend with the people I have in my life."

## **The Sontag factor: Why do we get sick? Just because, the late essayist taught us**

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Recently dead from cancer, writer and activist Susan Sontag is now an apparition at my shoulder guiding me through the daily news, a much smarter aunt, guiding my questions about almost everything: CBC reporter/anchor Wendy Mesley's breast cancer, actress Portia de Rossi stealing comedian Ellen Degeneres away from her long-time girlfriend, Nelson Mandela's son dying of AIDS and even the bloated bodies littering the shores of southeast Asia.

Sontag was a voice of moral clarity, not always correct, but always probing, penetrating. She died on Dec. 28 from leukemia.

"These stories about Wendy Mesley having cancer, we've trapped her, haven't we?" I mutter to my inner Sontag.



All of the recent stories about Mesley discovering she has breast cancer speak of her fight, her battle, her courage. The poor woman has already been enveloped by the cancer metaphor which demands that all its victims must courageously battle their illness and now she is chirpily embodying this requirement. To express a contrary sentiment -- outrage or submission or depression -- would be subversive. Cancer victims, such as Mesley, are also expected to accept blame.

Sontag drew attention to the cancer metaphor in her 1978 essay *Illness as Metaphor*, which she wrote after her first experience with cancer of the breast, lymphatic system and leg. After being diagnosed in 1976, she underwent a mastectomy and was pronounced free of the disease. In *Illness as Metaphor*, Sontag argued that illness becomes metaphorical when its cause is unknown. She wrote of how tuberculosis, in the 19th century, was considered a disease of sensitive, poetic, soul-sick people who were sent to sanitariums to wallow and convalesce. Only later, did scientists figure out it wasn't an illness caused by zeitgeist, but a bacterium. Because the cause of cancer is unknown, it also invites metaphor. While the TB personality was poetic, pale and submissive, the cancer personality is said to be uptight, perfectionist or passive. People who can't express their feelings or fail to stand up for themselves get cancer.

Embracing this line of thinking, I couldn't help but wonder if the TV anchor personality is cancerous, another archetype, making a mental list of all the TV anchors I have recently heard have breast cancer. Canada AM's Beverly Thomson, Balance TV's Dr. Marla Shapiro, CBC's Mesley, and countless others who were uncovered by a Google.

Just as TB was caused by a bacterium, not a poetic personality, someday it might be shown that it's not perfectionism or stress that gave the TV anchors cancer but the toxins, mystery ingredients and chemical estrogens in the cosmetics these women were forced to wear to look fresh-faced on TV. But for now, sufferers are prodded to look for a cause from within. Mesley told one interviewer about her search for a culprit.

"One of the oncologists told me she suspects steroids in milk. Another thinks it's all the chemicals and pesticides in our food. Some say it's stress. Other than some misguided habits of my youth, I've always been something of a health freak, exercising and trying to eat right. So I want to know, what did I do? What did I eat?"

"Just because" is simply not a good enough explanation. Sontag bristled at this thinking.

I read *Illness as Metaphor* 20 years ago, shortly after being diagnosed with lupus. While Sontag was persuasive, it didn't stop me from occasionally, sometimes obsessively, searching for blame for my disease and then assigning it to myself. Even today, after I've wrestled the chronic, degenerative illness into a tidy corner, I still obsess over what I might have done to have caused it. Like Mesley, I've wondered if I ate, drank or thought my illness into existence. Should I have eaten more broccoli, drunk less beer and stood up for myself more often?

It's my inner Sontag that helps me push these unhelpful thoughts away and accept an alternative explanation: Just because. It wasn't just Mesley's story that had me consulting Sontag, but also former South African president Nelson Mandela, who announced last week that his only surviving son had died of AIDS. He said he hoped to help South Africans begin to break through the heavy stigma that surrounds a disease, making it impossible to confront and treat.

Sontag also wrote about the metaphors attached to AIDS, complaining that the disease is either viewed as a modern-day plague or as an enemy invader. She hated the plague metaphor because plagues have always been thought of as punishments, therefore AIDS was metaphorically seen as punishing those who caught the disease. In South Africa's case, thinking of AIDS as a plague would be much better than what it is thought of now, as a disease worthy

only of whispers or silence. A military assault on the virus would be helpful, wouldn't it? How could Sontag not see that?

I thought of Sontag, too, when I saw the unfortunate victims washing up on the shores of southeast Asia. Her recent *Regarding the Pain of Others* considered the fact that modern life provides many opportunities to view atrocities. In it, she asked: Is the viewer's perception of reality eroded by the daily barrage of such images? What does it mean to care about the sufferings of people in faraway zones of conflict?

I thought of Sontag, too, when I read the news story (yes, this is news) that comedian and talk-show host Ellen Degeneres had been lured away from her live-in girlfriend by Portia De Rossi, the ice-queen from the TV sitcom *Ally McBeal*. Lawyers are allegedly involved, and De Rossi is being fingered as a predator of sorts. It all seems so common place, so heterosexual, so very Bennifer, that one would think that being lesbian is accepted in middle America.

But what about Sontag? Both the *New York Times* and the *Los Angeles Times* reported Sontag's death on their front pages but never mentioned her long-time companion, the famed photographer Annie Leibovitz, or her long relationships with other renowned female artists. These and other newspapers did discuss her mastectomy and a brief and long-ago marriage to a man. Was being lesbian too personal a detail? Only lately had Sontag publically described herself as bi-sexual, but never as a lesbian. I crave her insight into such silly stories as the Degeneres incident. And I crave an openness about her lesbianism that might have had the same affect on others as her essays on illness had on me.