

Choosing hope over fear

Lianne Hanson dreamed of having another baby. But keeping her ovaries was too big a risk

BY JODIE SINNEMA, THE EDMONTON JOURNAL FEBRUARY 15, 2009



Lianne Hanson after getting her head shaved before going into chemotherapy treatment for cancer.

Photograph by: Larry Wong, Edmonton Journal

Lianne Hanson sits in a baggy sweatshirt in the middle of her kitchen with a glass of red wine in her hand and tears glistening in her eyes.

Behind her, best friend Cara Obrigewitsch cuts through Hanson's long, blond ponytail with dull scissors before Dave, Cara's bald husband, begins his expert work with a razor. All the mirrors in the house have been taken down and the bathroom, with its fixed mirror, is off-limits until the hair-shaving session is complete.

"I want to take my hair on my own terms," says Hanson, 31, buoyed also by the liquid courage of a tequila shot. "This way, I make the rules."

Three months earlier, in October, Hanson wouldn't have dared be so brave. She was the girl who freaked out about hair lice, mice and meningitis.

Today, she is a survivor of genetic breast cancer who gave up both her breasts to prevent a recurrence, had them remade with muscles from her back in a 14-hour surgery and is starting a three-month chemotherapy regimen that will make her remaining dark roots fall out.

"I always thought of myself as a bit of a wimp and now I see myself as a woman of strength," says

Hanson, who has two wigs; one blond, the other a sassy Katie Holmes-style hairdo. "I really have a fighting spirit now that I didn't know I had before. And my faith, my relationship with God is stronger. I really believe He put this thing in my body to warn me, to save my life because I feel like I'm supposed to do something."

She doesn't want to frighten people about genetic breast cancer, since it's so rare.

"My story is not typical," she said. "(But) I could help somebody and that's huge. It's almost like being given an opportunity."

Hanson's BRCA1 genetic mutation, which astronomically increases her risk for breast and ovarian cancer, has led Hanson to make one final brutal decision: after chemo, she plans to have an oophorectomy, in which her ovaries will be taken out before ovarian cancer gains hold.

Making that decision was excruciating since Hanson and husband Jason dreamed of making a brother or sister for baby Abigail. Jason was willing to give up that dream when cancer infected his wife's right breast.

"Her safety is far more important than having a second kid," he says. "It feels like such a gamble and how do you gamble with a life?"

Throughout the last months, Jason's support has been constant. He's an apprentice plumber, but dropped out of the school portion in the fall so he could attend most of Hanson's medical appointments and bring in a bit of extra cash. During every stream of tears, he offered Lianne a smile and a hand squeeze. He remained an engaged parent when surgeries prevented Lianne from lifting Abby, and was the first to take off his trademark red ball cap, reveal his receding hairline and shave his head.

He insists he will always find Hanson attractive, breasts or no breasts, real or fake.

"It doesn't bother me," says Jason, 32. "I wish it was me. If I could take this from her, I absolutely would."

Hanson wasn't so quick to abandon the idea of a bigger family. She sat on the fence, trying to figure out how to get pregnant while running the 40- to 50-per-cent risk that cancer could begin growing on her ovaries while a baby grew inside her.

But two weeks after her double mastectomy and immediate reconstruction, Hanson received news that ended the waffling. Pathologists discovered she has lymphovascular invasion, where her cancer cells are entering vessels in her body that are so small that doctors have difficulty knowing if they're lymphatic or blood vessels.

That means Hanson's cancer may have spread through her blood or her lymphatic system, even though a November 2008 biopsy found no evidence of cancer cells in her lymph nodes.

Chemotherapy became a required rather than a precautionary measure, Hanson says.

"There's a small chance it may not be gone," she says. "When I found out the fact that it could be in my body, swimming around somewhere, it scared me enough to think ... why wouldn't I do anything when I have a high chance of getting ovarian cancer? I would rather be here for Jay and Abby than not be here for two kids and Jay."

Dr. Valerie Capstick, an Edmonton cancer surgeon who sees a lot of women with these genetic mutations, knows what's at stake.

No screening tests are good at finding ovarian cancer. No blood test, no vaginal or pelvic ultrasound consistently finds the cancer on time, she says. If physicians or patients rely on these tests too much, they can become overconfident.

"Plan a day for doing the oophorectomies because that's the only thing that's going to be protective," Capstick says. "Waiting until the test is abnormal, you've waited too long and your chance of cure is remarkably reduced the minute you have ovarian cancer and you're in serious trouble at that moment. It's so different from breast cancer, where the potential for cure is still quite good."

If Hanson has both her ovaries and Fallopian tubes removed in what is called a salpingo oophorectomy, she will reduce her risk of ovarian and Fallopian tube cancers by 85 to 95 per cent. Unfortunately, she will still have a five- to 15-per-cent chance (still higher than the average woman) of developing primary peritoneal cancer, which can grow on the surfaces in the abdomen.

Ovarian cancer is the beast that infected Hanson's grandmother in the late 1980s but went undiagnosed by her family doctor for months, despite unexplained bloating and painful pressure down her legs. Afterwards, the doctor apologized profusely, saying he had never before seen anyone with ovarian cancer.

The cancer is so hard to detect that most women aren't diagnosed until their cancer is in Stage 3 -- and Stage 4 is the worst. Only 23 to 41 per cent of women whose ovarian cancer is caught at Stage 3 are still alive after five years.

Inadequate screening isn't the only culprit. Doctors also have difficulty interpreting symptoms such as bloating, indigestion, constipation, painful sex or nausea, since they accompany so many different ailments.

For BRCA1 or BRCA2 patients, Capstick says, "The ultimate goal is get the ovaries out, but definitely what's up for discussion is the timing of it."

Young women should wait until after they have their families but before menopause, ideally by the time they reach 40 years old.

Yet even though the ovarian cancer risk is so high in the BRCA population, Capstick hears from women so scared of horrific hot flashes and mood changes brought on by surgically induced menopause, they consider postponing their prophylactic surgeries.

"There are women who have gotten ovarian cancer because of that," Capstick says. While some

doctors counsel patients with the cancer gene to avoid estrogen pills after an oophorectomy -- estrogen feeds some breast cancers and may spark growth -- Capstick believes taking hormone replacement therapy may offer some comfort to scared women, encourage them to plan their surgeries and actually decrease their elevated risk for breast cancer since the estrogen levels will never be as high as when they had their ovaries.

Not everyone in the medical community agrees. That leaves women who are considering prophylactic mastectomies or oophorectomies in the difficult position of having to make treatment choices based on complex and contradictory scientific evidence.

"For the cancer patient, it's really straightforward: this is what I have, this is what I have to do (to get healthy)," Capstick says. "For these women (with genetic mutations who aren't yet sick), it's much more complex. They're doing it to prevent a possible thing from happening to them. They have no idea if they will get cancer in the first place."

But cancer experts are noticing a disturbing trend: in about 10 per cent of prophylactic oophorectomies, pathologists are finding surprise tumours on the Fallopian tubes even though the ovaries remain healthy. If those reproductive organs hadn't been removed, then what?

Capstick has seen these tumours in the removed tubes of six or seven of her otherwise-healthy patients. The scientific community is now starting to wonder if ovarian cancer actually starts on the Fallopian tubes.

Wherever the cancer starts, Capstick feels her work helps.

"What I think of every time I do an operation with someone with BRCA1 that's preventative is that, back when we used to say it's a 50-per-cent risk (rather than today's 40 per cent) ... I would say, every two people I operate on, I have one less cancer patient to deal with. That gives a sense of satisfaction."

Most satisfying to Dr. Michael Sawyer, a clinical oncologist at the Cross Cancer Institute, would be finding a new screening test that would catch ovarian cancer earlier.

He and colleagues from Edmonton and Montreal have launched a research project in which they will collect urine for two to three years from 400 to 600 women at high risk of developing ovarian and breast cancer. Each urine sample will be analyzed in the hope that the chemical makeup of the woman represented in the urine sample will change as soon as cancer begins to grow, thus enabling doctors to act quickly.

"It looks very promising," Sawyer said, although he is skittish about one thing: what happens if the new test is so good it can pick up a chemical shift so quickly that the tumour can't be found with traditional imaging technology?

"That would be both terrifying to the patient and useful to them and the doctor," he says. They could then have urine tests done more often as a surveillance technique.

Sawyer and his team will also be searching for chemical shifts in people who develop breast, colon and

esophagus cancer. If his study succeeds, more studies with more women will need to be done with results far into the future.

Mammograms do a fairly good job of finding breast tumours early, Sawyer says, but can only be done once a year and are less effective in young women who have denser breast tissue. He's also concerned about the women who start getting mammograms at age 25 and are X-rayed every year during their lifetimes.

"You're irradiating tissue that is likely to become cancerous," says Sawyer, who remains an advocate of mammograms, but wants to find other options. "You're using to diagnose early the same thing that is part of the problem: radiation."

If women could hand over a urine sample, they could be screened more often. That's particularly useful for women with BRCA1 and BRCA2 genetic problems, since research has found they're at higher risk of developing interval screening breast tumours, which are caught in between regular mammograms. They typically cause painful symptoms but were absent on previous imaging, having grown in the short interval.

Hanson has a bigger dream that if her daughter, Abby, tests BRCA1-positive when she becomes an adult, she could receive a vaccine or pop a pill that could fix the mutation.

Sawyer says such a pill would be extremely challenging to develop and isn't the direction research is heading. He knows of only one drug that deactivates a protein in lymphoma patients. Deactivating the BRCA gene isn't an option, since every person has and needs that gene to work properly.

Some treatment drugs are being or have been developed that are particularly good at targeting cancers in BRCA people.

But Sawyer says the focus to help these women should be on better screening techniques, not cures for the genetic mutation. If new screening methods were found that caught 10 per cent more cancers at Stage 1 than Stage 2, or at Stage 2 than Stage 3 and so on, "we would make a big difference in the overall survival," he says.

Survival has been Hanson's goal, along with creating a broader awareness of what BRCA1 carriers face. That mimics the work of Christina Applegate, the actress who also had a prophylactic mastectomy and carries the cancer gene.

Such publicity and openness is the best thing that happened to breast cancer, says Dr. Kelly Dabbs, the surgeon who performed Hanson's double mastectomy.

"Before, people didn't talk about it," Dabbs says. When she first began seeing breast cancer patients, some would come in and say they suspected their mothers had breast cancer and mastectomies, but couldn't confirm it because no one spoke of the taboo subjects of breasts and cancer.

Now, pink ribbons are everywhere and thousands of people Run for the Cure.

Yet the public isn't as aware of the small number of women with the breast cancer gene.

Hanson's mother, Mary McDonald, says her brother thought Hanson was crazy for having both her diseased breast and her healthy breast cut off. In his mind, such drastic action was an overreaction instead of a way to reduce Hanson's high chances of getting more cancer.

McDonald says her brother might also carry the BRCA1 genetic mutation, but without testing, won't know if he's passed it along to his daughters. And without knowing their own risk, they can't be proactive in getting tests such as mammograms, McDonald says.

She says Hanson has already talked about becoming more involved with the Hereditary Breast and Ovarian Cancer Society of Alberta, the first of only two such advocacy organizations in Canada.

Joanne Riediger-Duebel, executive director of the society, says she and a small group of women created the society after feeling isolated and incredibly lonely while getting treatment.

"It was such a relief to find women who understood what this was like," says Riediger-Duebel, a 53-year-old BRCA2 carrier who has at least 12 family members who died of breast or ovarian cancer, including her mom and aunt, sister and cousin. When Riediger-Duebel had her breasts and ovaries surgically removed to prevent disease and death, she knew no one facing the same challenges. She phoned the Cross Cancer Institute to get an appointment with a psychologist, but realized she didn't qualify because she had never had cancer.

Over time, she encountered other women who would meet at kitchen tables or at Starbucks, where they would pile into the bathroom to show each other the results of their breast reconstructions.

In 2002, seven volunteers launched the society with \$500. In 2008, they spent \$60,000. They have members in Nova Scotia, Manitoba and B.C. and they attracted 124 people to their annual conference.

"People need to be aware this exists and self-analyze whether their family fits the profile," Riediger-Duebel says.

Once chemo is done, her nipples are re-formed and her body heals from the planned surgery to cut out her ovaries, Hanson intends to get a tattoo to mark the occasion. It will incorporate her daughter's name and the purple ribbon that represents the Hereditary Breast and Ovarian Cancer Society.

Even her four-year-old niece has started donating 50 cents of her weekly allowance to the cause.

"She said, 'Auntie Lianne, I'm going to fight breast cancer with you.' "

"I used to associate cancer with death," Hanson says. "(Now), I think hope." Especially in terms of Abigail, who celebrates her first birthday today.

"She has this chance of getting this gene, but I'm not going to be doom and gloom about it either. I refuse to. I spent too much of my life being that way. And ever since I had Abby, I realize that's crap. I'm not doing that anymore. There's too much to be happy about."

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