

The cost of cancer

Breast Cancer survivor Trude Huebner has a message for women in their 30s:

"Buy critical illness insurance while you're young, before you're diagnosed."

by Sandra Thomas-staff writer - published on 02/23/2007 – The Vancouver Courier

Source: <http://www.vancourier.com/issues07/024207/news/024207nn1.html>

Bustling about the kitchen of her small, but cheerful, East Broadway apartment, Trude Huebner brings a cup of tea to the dining room table and places it before a reporter. But the visitor already has a cup of coffee.

Realizing her mistake, Huebner and her good friend Merridith Porter, also seated at the table, both laugh and together say "chemo brain." Both women were diagnosed with a rare form of breast cancer called HER2-positive several years ago and met through a mutual friend.

Small in stature, Huebner is a youthful looking 60, despite battling a life-threatening illness for two years. Her dark hair is streaked with grey and worn short and spiky, an improvement over the bald head she sported for more than a year, when her hair fell out immediately after her first chemotherapy treatment.

"And I had just spent \$180 on streaks," says Huebner, laughing.

Huebner blames the treatment that took her hair as the cause of her short-term memory problems. Memory loss is one of many symptoms and complications Huebner, who has worked as a freelance writer and editor since 2001 after being laid off as a reporter at the National Post, didn't expect when diagnosed with breast cancer in 2004. But the most surprising complication wasn't hair loss or radiation burns. It was the crushing financial burden of surviving cancer.

Huebner went from working full-time to not working at all. She worried how she was going to pay her rent and bills and buy groceries. She was forced to use up her savings and RRSPs.

"Even though I live a frugal life I have been wiped out financially," says Huebner.

She spent \$10,000 of her savings in four months and there were times she had to borrow from friends to pay her rent

The cost of surviving any type of cancer can be devastating. But breast cancer affects mostly women, many of whom are underemployed, underinsured or have no safety net. While basic life-saving drugs are covered by provincial medical services, patients pay for many treatment costs and complementary therapies either out of their own pocket or through their private insurance plans. Few women are prepared to face the cost.

"If I can use this article to get one message out there," says Huebner, "it's to tell women in their 30s to buy critical illness insurance while they're young and before they're diagnosed. Forget those expensive shoes and spend the money on insurance. Once you're diagnosed with breast cancer, you're uninsurable."

According to Sue O'Reilly, vice-president of cancer care for the B.C. Cancer Agency, curative drugs associated with cancer are covered by the B.C. health plan, which dedicates \$100 million annually to curative drug funding in B.C. For cancer patients living on social assistance, medications including anti-nausea drugs and antibiotics are free, while seniors pay a minimum deductible.

But for the majority of women with breast cancer, the costs associated and created by treatment can quickly erode their finances.

According to a study by the Ontario Breast Cancer Community Research Initiative, unanticipated expenses include paying for anti-nausea drugs, pain killers, dispensing fees, transportation and parking, child care and house cleaning. Some anti-nausea drugs run as high as \$100 a pill, while the dispensing fee for some intravenous drugs ranges between \$250 and \$350 each time they're administered. In some cases the drugs are given 10 to 14 times during treatment.

Huebner points to a tube of toothpaste on her dining room table. The \$12 tube is one of many specialty products, including creams and lotions, to alleviate the physical symptoms of chemotherapy.

"You lose all your secretions including saliva and ear wax," says Huebner. "You have no tears and your nostrils dry up. You have to buy lubrication for every orifice in your body."

For the first few months of her illness, Huebner faced treatment costs alone. But she had also gotten a job as a part-time medical courier for Lion's Gate Hospital, and her employer allowed her to buy into the hospital's extended medical plan provided she paid the full \$120 a month cost.

Huebner, who lives alone, says the loss of wages hit her the hardest when she was too ill to work. According to the Ontario study, many women work while sick or fatigued due to the side effects from treatment such as chemotherapy, because they couldn't afford to take time off work. Cancer patients typically lose an average of 12.6 work days per month and their caregivers an average of seven days.

Huebner's bills piled up, including prescriptions for the anti-nausea drug which cost \$25 a pill. When those pills didn't help, she turned to the Compassion Club, a local group that sells medical marijuana-based baked goods. Instead of paying \$25 per pill, Huebner paid \$36 for a dozen cookies.

"They were a life saver, even though the cookies tasted like dog kibble," says Huebner, with a grin. "And they kept me off the street."

Huebner also tried acupuncture as an alternate to pain medication, part of which she had to pay. She also pays \$60 an hour for massage, which she calls vital to her health, and attends a rehabilitation exercise class to regain strength in her right arm and shoulder after they were damaged during her lumpectomy and surgery to remove nodes from her armpit to her wrist.

Lynda Balneaves, a research scientist at UBC School of Nursing, is part of a team completing a study on early-stage breast cancer and beginning a study on advanced breast cancer. She says the financial stress the disease forces on women fighting breast cancer is great.

"Once they're diagnosed with breast cancer women go through surgery, chemotherapy and radiation if necessary," she says. "After six months they're basically told off you go, but people don't realize the fatigue from the treatment can last a year. They can only hope they can make it back to work, but for some going back to a full-time job isn't possible. God bless these women for trying to get back on their feet."

Huebner considers herself lucky. She had occasional free access to a vehicle for some of her appointments, including chemotherapy, through the Freemasons Cancer Car Program. The car, she notes, came complete with airline barf bags.

She was also one of the first patients in B.C. chosen for an early trial of the breast cancer drug Herceptin, a medication that when combined with traditional chemotherapy can reduce the chance of relapse from 33 to 15 per cent. It turned a death sentence into hope.

But finding hope can be hard because few employers are willing to take a chance on an employee with cancer. Many won't hire people after treatment because of the cost of insurance premiums.

Even home-based workers such as Huebner have a tougher time. Although she doesn't have to face an office full of people or get dressed for work if she lacks the strength, she was recently hit with an awkward question by a client offering her work.

"Basically he wanted to know what would happen if I died before the contract was finished," says Huebner. "So I had to arrange to have another editor on standby in case that happens."

Balneaves' research revealed many women had to decide between treatment and wages.

"We found in the South Asian community some women diagnosed with breast cancer work for an hourly wage and were afraid to take time off," she says. "Many of them don't drive and even the person driving them is losing wages by taking time off to pick them up."

Merridith Porter faced an uphill struggle when she tried to go back to her job after her cancer treatment. Taller and younger than Huebner, with a chemo-induced short haircut that replaced what was once waist-length hair, she worked for a decade for a large health union as a senior clerk. Porter won't name the union because she's considering filing a human rights complaint against her employer. The complaint is on hold because she needs all her energy to continue her battle against cancer.

"When I was first diagnosed my co-workers rallied around me," says Porter, who was diagnosed in 2003. "My employer even sent me on a couple of days holidays to get over the shock."

That kindness didn't last and Porter soon realized she needed to return to work as soon as possible during treatment to keep her job. In her absence her job description was changed to data entry and she was forced to re-apply for her position. As part of her job interview Porter had to complete tasks on a computer.

"I hadn't been to work for 18 months and my test was the day after a chemo session and I had severe chemo brain," says Porter. "To make matters worse they disabled the spell check. I was told point blank after that, that my options for promotion were non-existent."

Porter filed a grievance and left the union, but has been unemployed for more than a year.

Her experience is not unusual. Balneaves' research found many women's jobs change while they are off getting treatment. And their employers and co-workers no longer trust them with important work.

"She'll find she's not being included in long-term projects anymore and she's not being given certain tasks," she says. "The fear is she's not going to be around for very long. It's hard to get promoted if your employer thinks you're going to die."

Porter says she's extremely lucky to have a partner who has stuck by her supporting her not only emotionally, but also financially.

"That doesn't happen very often," she says. "In my support group I heard from women all the time who were left alone after their boyfriend or husband left them. How many men want to stick around and go down the financial tube with you, and in lots of cases that's also the end of a woman's extended medical coverage."

She says no one wants to hire a cancer survivor because the costs for insurance is prohibitive and there's always the chance the person will get sick again.

"And there's no way you'll pass a physical," says Porter.

Luckily Porter was covered by extended medical during her treatment and initially had long-term disability insurance. Her extended medical plan paid for the drug Neupogen, which stimulates the production of white blood cells and strengthens immune systems battered by chemotherapy. By increasing a patient's ability to take more chemotherapy in a shorter space of time, it also increases survival rates.

"While you're getting chemo you sit in a chair and talk to the other people getting chemo," says Porter, who had her last chemo session in December. "I found out some people were paying \$5,000 a month for Neupogen and some others weren't taking it because they couldn't afford it. I was really lucky."

Porter was also lucky enough to be included in an experimental trial of Herceptin, which is now covered by the B.C. medical services plan.

"Even if you can afford to pay for the drug, the cost of the infusion isn't included," says Porter. "That can be \$250 or more every three weeks and you have to pay in cash."

Porter says her loss of employment and the financial toll she's paid adds to the crippling pain, rashes, hot flashes, increased urination and loss of one breast through a mastectomy.

"Some days I would scream with rage and weep with despair."

Realtor Catherine Chauvin channelled her rage and despair into action.

Sitting in a West Side coffee shop, Chauvin sips a cup of tea and recalls how her battle with breast cancer began 16 years ago. The 55-year-old also looks surprisingly good. Her salt- and pepper-coloured hair is short and spiky, having recently grown back after chemotherapy, her skin is clear and her eyes bright. Dressed in a suit and overcoat, she looks the part of a successful realtor and not someone who was close to death a year ago.

When she was diagnosed with breast cancer, her doctor told her to make a will. Chauvin, then living in Victoria, chose to fight and suffered through chemo and radiation therapy. She didn't expect to survive.

"But I made it to the five-year point and that gave me some hope," she says.

That battle cost her dearly. Surgery to remove the nodes under her right arm severed two nerves and ended her ability to play cello and viola with an amateur orchestra. She also lost her job. She says while her former employer couldn't legally fire her after her extended absence, the company did everything in its power to make sure she didn't return. Chauvin filed a human rights complaint against the company, which she won't name, but like Porter, she's put the suit on hold because she needs her energy for her recovery.

"It was obvious they didn't want me back," says Chauvin, who is divorced and lives on her own. "I ended up with no job and it cost me my life savings."

She moved to Vancouver and found another job as a realtor, facing the same difficulty in finding an employer willing to hire a worker with cancer. But then swelling in her arm and a bloody discharge from her nipple led to news she didn't want to hear, when she returned to her doctor for a mammogram-which showed nothing- and an ultrasound and MRI.

"They did a needle biopsy and I was told I had stage three cancer. Cancer has four stages with four being terminal," says Chauvin. "I was told I had a seven-centimetre tumour and it was inoperable."

The news couldn't have come at a worse time. Her company was sold two weeks before her diagnosis, leaving her weeks short of qualifying for long-term disability.

"You had to have worked for the company for 90 days to qualify," says Chauvin. "And I was short."

With no financial resources available, Chauvin worked through five months of chemotherapy and missed only four days of work. The anti-nausea pills she needed to get through the chemo were \$20 a pill, but she had no money to buy them. Then a pharmacist mentioned a B.C. Cancer Agency program through which she could get the pills at no charge thanks to a donation made by the family of a deceased patient. Patients with very limited incomes can also apply for some financial assistance through the agency.

"They would have cost me several thousand dollars a month," says Chauvin, who completed chemotherapy one year ago. "But you have to have them. Imagine the worst flu you ever had in your life and multiply that by 100. That's what chemotherapy was like for me."

While Chauvin worked through five months of chemo, by the end of her treatment she was exhausted. "I couldn't work," she says. "By the end of the five months I had no immune system. It was equivalent to having full-blown AIDS."

The chemotherapy was unsuccessful. The seven tumors did not shrink and an additional tumor appeared.

Her oncologists insisted she have a mastectomy. But Chauvin has refused to this day. Having gone back to work six months ago, and having used up her savings for the second time, Chauvin can't afford the time off from work to recover from the operation.

"It took me 10 years to build my savings back up and now it's all gone," she says. "There's no one to take care of me. How will I pay my rent? How can I pay a housecleaner and who's going to buy my groceries? I had a very good lifestyle before, but my first bout of cancer wiped me out, I was almost homeless. These are just some of the things you have to worry about."

Chauvin also suffers from depression and takes anti-depressants, which cost \$140 a month.

Angry and disappointed after the chemo, she explored alternative and complementary therapies. She contacted the Centre for Integrated Healing in Vancouver and attended a free information session. What she learned that day convinced her the centre offered something she hadn't felt for a while—hope.

"Somehow I scraped together the \$375 for the two-day integrated cancer care seminar and I've been attending ever since," she says. "I've embraced the program. It made sense to me and really, what have I got to lose."

Chauvin changed her diet, attends yoga classes and took supplements. She spends \$1,000 a month on organic food and supplements, but is convinced the effort is worth every penny.

"Quality of life might come at a price, but two weeks ago I went for an MRI and I was told my tumors are shrinking," says Chauvin. "I find the cost is worth it."

The Ontario study recommended several suggestions to help women with breast cancer, including making the public aware of the financial cost of cancer and that women with cancer need practical support such as child care, house-cleaning services, and help paying for everything from parking to drug dispensing fees. Women must also be made aware of services, such as the free transportation made available through the Canadian Cancer Society.

The study recommended that women be given flexible back-to-work arrangements and help understanding public and private insurance application forms and adjudication. Chauvin wants the provincial medical services plan to include more alternative and complementary therapies in its coverage.

"We should each have our own medical savings account and if we get sick it should be up to us to decide how that money is spent," says Chauvin. "Some people might choose the \$70,000 chemotherapy anyway, but others like myself might want to spend it on other therapies."

But Chauvin no longer worries about being cured of breast cancer and wants to make the rest of her years as full of dignity, happiness and well-being as possible. She spends every penny she has after rent on the complementary therapies she believes are helping her survive.

"My goal now is simply quality of life," she says. "Every day I wake up I'm thankful. I've lost almost everything I own, but I am truly glad to have each day. It's great to be alive."

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