# Seven Reflections on Breast Cancer by Seven Women Who Worked Together

## SHARON ANGEL, TERESA HEALY, SANDI HOWELL, LAURIE KINGSTON, CATHERINE LOULI, DOREEN MEYER AND CATHY REMUS

Nous sommes sept soeurs syndiquées qui se connaissent à travers notre travail dans le bureau national d'un syndicat du secteur public. Entre 1997 et 2006, on a repéré chez l'une après l'autre, un cancer.du sein. Quoique nous nous connaissions et avions joué un rôle plus ou moins important dans notre vie, nous n'avions jamais véritablement parlé de nos expériences de la maladie jusqu'à ce qu'une d'entre nous suggère d'en parler par écrit. Nous avons passé deux années à écrire, à en parler, à manger, à se rappeler, à analyser et à écrire encore et toujours. Ce texte est une petit extrait de ces deux années d'écriture. Ensemble et à part. Sur un thème commun mais séparées.

We are seven union sisters who know each other through our work in the national office of a public sector union. We are researchers, communication specialists, educators, a job evaluation specialist and a director.

Between 1997 and 2006, one by one, we were diagnosed with breast cancer. We each started off on our unique journeys through treatment, conscious of the privilege in our situation—the generous leave provisions and benefits package at work, and the excellent cancer treatment (both medical and alternative) we could access in Ottawa.

Although we knew each other and played major or minor roles in each other's stories, we never actually came together to talk about our breast cancer experiences until one of us suggested we write together. We spent two years writing, talking, eating, remembering, analyzing, and writing some more. The process was, at moments, rich and enriching, difficult and easy, supportive and challenging, focused and wonderfully all over the map.

Even though we knew each other and saw each other in various combinations for various activities on a more or less regular basis, writing together taught each of us so much. We learned that we shared many experiences that we thought were unique, and that we each had our unique experiences that we thought were common. We learned that we were seven distinct voices with seven distinct stories who were connected by a multitude of shared references

unique to our workplace. We are a group who would never run out of things to talk about.

This is a tiny sampling of two years of writing. Together and apart. On both common and separate themes.

## What Really Happened During Treatment? Teresa Healy

What really happened during treatment was that I had to cancel the paper. After months of putting unread pages down beside the stack of yesterday's news, I thought I should stop adding needlessly to the recycling bin. The big black headlines were meaningless and jumbled. I could see only separate words floating in sea of print.

What really happened during treatment was that I swelled up and became slow and heavy. Heavy in thought and heavy in body. I remember looking at myself without hair and knew that I was exposed to the world, not as a bald man who had shaved his head to present himself in the world of ideas but as a woman going to a conference who couldn't even read a newspaper. But I went anyway.

As I made this trip, I was lost between a scarf that didn't fit, and my wig, all heat and itch. I think I left it in the closet. I saw the bald professor walk by with a cigarette. He crushed it in the sand held in the silver urn in the hallway. I wondered what the difference was between us.

I sat down at the back of a hall, head-naked in a room full of realists talking about states as unitary, rational actors. They were indeed self-contained and self-interested. Their words were the billiard balls that bounced off each other and anarchy did preside. My female head, also shiny and round, was embodied in rebelliousness. I was in the wrong room.

I felt out of time. I covered my head again. I went for a walk along the water's edge looking for mini sugar doughnuts and feather masks. The conference carried on without me. I welcomed the warm sun on my face. I sat on a park bench. What really happened during treatment was that chemo blew holes in my brain and corroded my spongy soft tissue. Like acid, it ate away at what was there and could no longer be. It was chemo that saved me, perhaps, but chemo that asked me to vacate my body for a while, leaving me to live in my eyes.

What really happened during treatment was that words could only come to me in wild ways. Often in the company of my sisters. I could, every once in a while, capture stray thoughts. Drops of life condensed in my pen. Wisps of my past wanted to be reminded to me. Alone and in carry on without her; and I am in remission and continue a course of treatment that finds me in the chemo room every 21 days.

What really happened during treatment was that I became intimate with vulnerability. The thought of not being around to raise my daughter made my heart ache. It was unbearable to believe that this was a possibility. Suddenly at age 39 my mortality was very real. I was exposed to a host of medical practionners and clinicians, and cradled with love by friends and family. It was during that year that I understood the words "in sickness and in health"

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company, images played with me and I could sometimes remember that I was a woman in love with words and words might again lead me to life.

### What Really Happened During Treatment? Catherine Louli

I was diagnosed with breast cancer in 2001, following on the heels of my 39th birthday. Up until that moment I had by and large lived a charmed existence. I was the kind of woman where nothing seemed daunting; I was young, strong and loved life. Unbeknownst to me I also had rapidly growing malignant cells taking hold inside my breast. I had no idea what lay ahead of me. I remember frantically trying to reach a colleague of mine—a union sister, who had been diagnosed with breast cancer a mere three weeks earlier. We were numbers two and three of what would become seven women working in the same building diagnosed with breast cancer. When I reached Teresa, her voice was soothing, calm, and she was unsure of what was to come next. I then phoned a mum at my daughter's school. Our daughters were in Grade 1 and had been together since Junior Kindergarten. And we were developing a nice friendship ourselves—us mums. Unbelievably, she too had recently been diagnosed with breast cancer—hers was a recurrence. The first time round she had the type of breast cancer that never comes back—still in the milk duct and ever so tiny. Kathy McDougall was lovely, truly beautiful inside and out. She told me not to let the fear swallow me up, "it clouds your thinking and you need to think clearly now."

The three of us women had very different treatments, prognosis and outcomes. Teresa is thriving and cancer free for eight years now, Kathy died in May 2003 leaving her soon to be seven-year-old daughter and husband to

and regretfully understood that it did not hold true in my marriage. It was during the first year of treatment that I lost my innocence. What really happened during treatment was that I had to overcome my natural modesty and allow all manner of health professional to manipulate my breast into a radiation breast plate, or a mammogram shield, or allow a surgeon to cut into my breast to remove cancerous tumours. I allowed women I had never met to pierce my skin with needles time and again. I wept in strangers' arms, and laughed with technicians I had never previously met. What really happened in treatment is that through a magical combination of luck and medical intervention I survived it, and I continue to do so. My daughter turned five in 2001, this year in 2011, she will be 15 and I will celebrate 49.

#### Pink Doreen Meyer

Pink. Oh, so political. Pink for girl. Pink for breast cancer. That fleshy colour pink.

I heard the radio interviewer question his guest on the history of pink. Little girls being marketed to: pink dresses, pink bedspreads, pink rooms. Pink, not blue.

The radio guest said historically blue was the "proper" colour for young ladies. I dislike pink and I'm not that crazy about blue, either. I like real intense colours, jewel tones.

But pink does make me crazy. Just like the Barbie craze, though I have my own big breasted, non-existent-waisted Barbie. I fashion dressed her when I was ten. I kept her, thinking someday I'd share it with my daughter. No daughter. I hear my friend and coworker talking about her daughter and the love for Barbie and her accessories. Successful sales pitch is more like it, like that pitch for pink.

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Why pink for breast cancer? Pink boobs? Pink and polite as women of a certain age were taught, brought up to be? 'Now dear, the doctor knows best.' All those experts, usually guys, who would never wear pink.

Pink turns it into a product. Nice package breast cancer. Wrap it up in pink. Don't think about where it comes from, what goes wrong below the pink flesh. March. Run for the cure. Be a good sport. Pink to get cold, hard cash green.

Big money, that pink. We can sell anything to women and their daughters, they think. Big money to market it, brand it and us. Do we buy without even knowing the true cost of submission? Otherwise, we'd be waving red flags out of anger, demanding more out of life for generations of women brought up in pink.

Why, when women the world over are suffering with breast cancer, is it pink that gets to be the symbol for a gender, a symbol for a disease?

Pink is political only to those of us who feel ill-painted with it. Too pale, too washed out, too diluted, too much a watering down of healthy blood red for my liking.

Pink has a purpose and it's not benign. Stereotypes can harm us; we women who are encouraged to think pink and not think about being political or being activists who demand change. Change of thinking about why there is breast cancer at all and why too many women are wearing it.

Pink really makes me sad. Sad for the future and those little girls in the pink bedrooms with pink Barbie backpacks. And all those pink ribbons that will wave in the breeze, so prettily, above our graves.

#### Pink Sharon Angel

I find the colour pink such a turnoff. I associate it with a concept of femininity that does not resonate with me. I have never "done" frilly or lacy and for me pink has a similar sensibility. I love the degree of mobilization that has taken place around this awful disease and the strength of the voices of those representing breast cancer organizations (most of which make use of the well-known pink ribbon symbol). They speak to me of what women can do when they come together around an issue. But pink has always represented for me something which is the complete opposite—Barbie dolls and women's "delicate nature." Ironically, according to a recent CBC radio documentary, at the turn of the last century the colour blue was considered more suitable for girls and pink for boys.

Although never a fan of pink, after being diagnosed with breast cancer I have developed a deep aversion to the cotton candy shade associated with the disease. In part this is due to the commodification of breast cancer, especially the ubiquitous pink products sold every October, Breast Cancer Awareness Month.

In 2006, my first October as a "survivor," I was over-

whelmed when I went into stores and found display counters with pink items for sale, always with an accompanying sign indicating that a portion of sales from the products would go to "breast cancer research". Rarely was there any indication of what portion of the sales would be donated and to what organizations. In October 2007 my local pet store had a huge breast cancer logo in its window and was selling pink products. My local pet store! I parked my car beside an air pump as I went into a convenience store. The air pump had a breast cancer logo! "Part of the sale of this air will go to breast cancer research?" I also went into a large department store with a big pink display (including a nine foot foam breast cancer logo hanging from the ceiling). I was there to buy a mastectomy bra. In Ontario mastectomy bras are supposed to be tax-free. No-one including the manager knew this. She charged me tax but at least agreed to look into the matter. Educating her a little and her responsiveness made me feel somewhat better.

Having such a strong aversion to pink is probably not useful, especially in October. Maybe I need to develop more equanimity around this issue. I would be helped a lot in this challenge if every breast cancer organization world-wide declared a moratorium on the colour and selling pink items in the name of breast cancer was made illegal. Okay, not going to happen. Perhaps I need to re-appropriate the colour for myself by buying a really fabulous pink non-frilly, non-lacy piece of clothing in March!

#### Snap Shots Laurie Kingston

December 2, 2006

When I close my eyes, I see myself as I was then.

Short dark hair and boots with heels.

Irritable and excited in equal measure.

I knew big change was coming. And it did. But it was not what I expected.

I was getting undressed when I found the lump.

July 1, 2006

I close my eyes and see myself as I was then.

Round, bald and bloated. But happy. Chemo is behind me. Or so I expect.

Chemo is benind life. Of so I expect.

I am self-conscious but also hungry.

I eat two burgers at the barbecue.

#### December 24, 2006

I close my eyes and see myself as I was.

I rallied for Christmas Eve but in the end the pain got the best of me.

My liver was riddled with tumours. And I had waited too long for the morphine.

My mother had to put me to bed.

That comforted me.

And so did the drugs.

June 25, 2007

I close my eyes and I can taste
The strawberries on my tongue
The sensual pleasure of the whipped cream
And the Niagara ice wine as it slid down my throat.
I knew I would soon have something to celebrate.

#### December 16, 2009

I close my eyes so I can think.
I have now been in remission for 30 months.
And I will be in treatment for the rest of my life.
Some days I wake up celebrating.
Some days I grieve for what I have lost.
Today is a sad day.
Tomorrow will be better. Or maybe the day after that.

## The Bell Cathy Remus

There's a tarnished brass bell in the chemo room. It hangs from an intricate wrought iron brace near the nursing station. A woman pulls the cord, ringing the bell on her way out, a chemo room ritual to celebrate her last round of chemo. She smiles, her partner wipes a tear from his eye. Nurses call out congratulations, patients clap quietly, she walks out with hopeful eyes.

The ringing of the bell in the chemo room marks the beginning of a rite of passage, from cancer patient to survivor—even if more treatment awaits, even if radiation, surgery, hormone therapy will each assault the body in its own way. Finishing chemotherapy, so ravishing and feared, calls for ceremony and celebration and hope for the future. After all, would any of us go through the side effects if we didn't believe it would put us among the survivors?

Laurie snoozes, curled up under the soft pink blanket that she brings to every treatment. The nurses told her she won it in a chemo room draw. She suspects they conspired to award it to her in honour of her ongoing presence where most people spend much less time. She's sleepy and stoned on her special recipe of gravol, demerol, vinorelbine and herceptin, with a pinch of a few other pharmaceuticals thrown in for good measure. Just dozing off when the bell rings, she smiles sleepily, belying the bitter sweetness of the sound for someone with metastatic breast cancer.

When Laurie finished her first round of treatment, there wasn't a bell in the chemo room. Now each ring is a reminder that lifelong visits there might end up being her best case scenario. She might never get to ring the bell and leave it all behind her—at least not the way the ceremony works now.

Laurie and I walked an identical road for awhile. Like me, Laurie left the chemo room several years ago after what was meant to be her last chemo treatment. She felt the euphoric relief of completing chemo and the hopefulness of soon being able to put cancer behind her. She went through radiation and a recovery period, enjoying the sensation of hair growing back, energy levels returning, and life returning slowly but surely to "normal". She started back to work in a modified return to work program in a job she loved, doing meaningful, challenging, political work on behalf of the workers her union employer represents.

The bell wasn't here when I finished chemo, either. I celebrated with my family and my oldest friend who travelled from Vancouver for the last treatment. My sister prepared a special meal. Seven years later, the scars have faded, my shoulder and arm can stretch like they used to, my energy has returned, and, finally, my shinier, lighter, straighter hair is back, replacing the wiry dark hair that chemo grew. I don't think about cancer every day anymore, and I don't feel drawn to books and talks and media reports about cancer.

I imagine Laurie waking after her treatment, packing up her pink blanket, and walking over to ring the bell on her way out. The nurses smile. The patients clap quietly. Instead of "I'm done", the ringing of the bell says "I'm here." She walks out, heads home to life, a partner, sons, friends, blogging, writing, reading, knitting, walks with the dogs and laughter and love to feed her soul.

There are no guarantees in the chemo room, just as there are no guarantees in life. What I've learned from breast cancer is that every precious moment, spent with whoever is nearby, doing whatever is happening, matters. Every moment deserves a ringing of the bell.

#### Work Sandi Howell

Each time we meet, my heart is assaulted by wrenching stories about the toxic work environment we share(d). How could anyone deny its impact on our health? Its seepage into our tissues, like the tar sands, seeping into the water table. Eating away.

Or, is it us? Do we transform the experience by turning inward, stewing about the day's frustrations, humiliations and bad leadership?

Why do some get cancer and others not? Some unscathed, others stricken? Is it in our genes? Is it in our souls to respond this way? After all, we are in the "business" of fighting injustice.

It doesn't stop at home. There is no brick wall to protect us from the slings and arrows of fellow travellers. Or worse, their hard-hearted indifference. Perhaps we are not fellow travellers on the same path, after all. Why does the path change for those in power? Did they achieve power on a pretense, and once giddy with it, their ego path unveils itself? They are now part of the power elite, whose job is to maintain the status quo, contain the complainers, especially, if the complaints are about them. They co-opt the bright young stars among us. Or discourage those with ideas worthy of changing the world, their world.

We work for something different.

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We have learned from our experience. Though our cancers may arise from multiple elements, we know the work environment is a major contributor. We are writing together about what we have learned. We want others to benefit by joining together to take on stonewalling bosses.

We want to turn anger into action for change by telling beautiful, powerful, transformative, stories.

We are humanitarians, compassionate women, women who have faced death, women who have worked hard, raised families, contributed to our communities, faced adversity, made music.

We are strong women, who make unions strong. We want our stories to make a difference.

Sharon Angel is a job evaluation specialist with the Canadian Union of Public Employees (CUPE). She has recently returned to work after undergoing treatment for a recurrence of her breast cancer. Sharon lives in Aylmer, Quebec in a little cottage near the Ottawa River, where her wonderful friends came to look after her.

Teresa Healy is a writer, a researcher in the labour movement and a singer-songwriter living in Ottawa. She is the author of Gendered Struggles Against Globalisation in Mexico (Ashgate, 2008) and editor of the Harper Record (Canadian Centre for Policy Alternatives, 2008). As part of the folk duo Healy & Juravich,, she performs songs about work, love and struggle. She is now working on her next CD project due out later this year. Boot Against Nettle is a collection of songs about life as an Irish-Canadian woman which she began to write during treatment. <www.teresahealy.ca>.

Sandi Howell is the recently retired Director of Equality for CUPE. She lives with her partner, on the Tay River, where she wanders happily in the woods, reads, travels, and enjoys the company of purring cats on her lap.

Laurie Kingston is a 43-year-old mother, writer, trade unionist and wife who was diagnosed with metastatic breast cancer in 2006. She's been in remission since June 2007 and continues with monthly treatments. Laurie writes a blog called "Not Just About Cancer" and has written a book about her experiences called Not Done Yet: Living Through Breast Cancer, which was published by Women's Press in 2009. She lives in Ottawa with her two sons (who are seven and twelve years old), her husband, and her Tibetan Terrier.

Catherine Louli is a writer living in Ottawa. She is thrilled to be alive and raising her daughter Emma. She works full time for CUPE, and continues a course of treatment to keep cancer at bay. Catherine remains in awe of the mysteries of the universe.

Doreen Meyer is a recent retiree celebrating more than 13 years of being cancer free. As well as writing, she enjoys photography and stitching and is a member of the Out of the Box fibre artists.

At 51, and eight years past being diagnosed with breast cancer, Cathy Remus loves life more with every year that goes by. As a labour educator, she is constantly inspired by the members and staff she gets to work with in CUPE and the broader labour movement. She credits her family and friends for loving the cancer away and for continuing to enrich her life in so many ways.

#### **JOAN BOND**

#### **Chronic Fatigue**

One sofa cushion wearing thin where her tail bone rests month after month. The days' weight pulls her face away from the window toward documentaries, needlepoint, biography.

She knows not to wait for that home-town man to unhinge the gate, walk on the front lawn, the first stair.

Nowadays visitors knock, enter with flowers, prescriptions, chocolate cake slices, thin as her smile. They know casseroles turn her stomach. On occasion her mouth moves upward, recommending reading material or tourist attractions, places she was when getting into a car wasn't the journey itself.

She wants to give back by taking in her visitors' well-intentioned gifts and errands; even disclosures that they are tired of their lives crammed inside marked calendars. Lying on a couch, watching TV alone, eating almonds and cashews for protein sounds good to them, a secret they wouldn't speak out loud.

Home Care workers and the cleaning lady know what's in her cupboards, closet, refrigerator; her life like crushed ice melting into others.

Joan Bond resides on the prairies where she writes poetry and paints in watercolours. She has published in The Antigonish Review, Prairie Fire, FreeFall, The Nashwaak Review, and previously in Canadian Woman Studies. She is a late bloomer, stepping into her prime.