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# I am a woman who lives with breast cancer

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I am a woman, and I am a woman who lives with breast cancer, and I am a woman who lives with breast cancer in Mexico.\* Being a woman defines much of what I am experiencing, as well as my approach to treatment and the choices I have made. Living the disease in Mexico has allowed me to identify the need for collective action by and for women, to meet the challenges of this disease in Latin America.

In this personal testimony, up to June 2008, I will focus on three issues: the personal and family realm; the key elements of my medical treatment that have given me courage and stamina; and why I have converted my personal experience into a programme to combat the breast cancer epidemic that is plaguing Mexico and Latin America. In each of these, I reflect on what I think are key issues for the health of women.

## My breast cancer experience to date<sup>†</sup>

I had my first routine mammogram in Cuernavaca on 27 October 2007. On 6 November, the diagnosis of breast cancer was confirmed. I was 41.

I will describe my medical situation from the perspective of a person who has read substantially on the topic, keeps careful medical records,

\*I was inspired by the following from Austveg: "In the preface to her book *The Second Sex*, Simone de Beauvoir wrote the famous sentence: 'I am a woman.' With this, she not only states an obvious fact, but also positions herself in relation to what she discusses in the book... I am not sure if positioning oneself is necessary as often as we tend to think it is. But sometimes it is, as it has to do with honesty and scientific decency."<sup>1</sup>

<sup>†</sup>For information on staging criteria, medications and other terminology referred to in the text see refs 2 and 3.

works in the health sector, and has a PhD in economics, but is not a physician and has no medical training.

My breast cancer was identified somewhere between stage one and early stage two. At diagnosis I had two malignant tumours on the upper left quadrant of my left breast spanning 2.5 cm and 1.3 cm and substantial invasive ductal carcinoma.

My tumours were (it is important to use the past tense, since they are now out of me and pasted onto laboratory slides) positive for HER2 overexpression, as well as oestrogen and progesterone receptor expression. Despite my Ashkenazi Jewish heritage, I am BRCA-1/2 negative and there is no history of breast cancer in my immediate family. While I am node-negative according to current staging criteria, some isolated cancer cells were located in one lymph node.

In the four weeks after my diagnosis, I had three operations. The first was the most frightening. While only a segment of my left breast was removed, so were five nodes. Unfortunately, one of the margins continued to show the presence of invasive cancer. My second operation, performed two weeks later, was to remove another segment in an attempt to leave all margins clear of cancer. Unfortunately, one margin continued to show infiltration, and an additional, relatively large mass, although non-malignant, was later identified in the lower right quadrant. Combined with the invasive margin, this made mastectomy advisable.

The mastectomy, performed on 5 December, was by far the most painful of the surgeries, but not the most frightening. The result is a scar that looks like a frown (or an upside-down smile) that runs across the place where my breast used to be. I am not large-breasted, so a small cushion stuffed

into my bra or top works relatively well to achieve symmetry post-mastectomy.

My last, and least difficult, surgical intervention of 2007 was the insertion of a catheter on the right side of my chest to facilitate chemotherapy infusion. The result is a smaller scar, with a button-shaped piece of metal underneath. This looks, and feels, a bit like a doorbell beside my bra strap.

I am in the process of having my left breast reconstructed. Immediately following the skin-sparing mastectomy, an expander was inserted and fixed to the muscular tissue. This feels a bit like a hot water bottle sewn to my chest wall. There is another "doorbell" placed strategically under my left arm, right where a bra should pass. On a not-so-regular basis, since I have been concentrating much more on getting through chemotherapy, water is injected through the "doorbell" to gradually make a space for a permanent implant. I must prepare for at least one more operation to remove the expander, insert the implant and "adjust" the other breast. Having had several expansions, I am convinced that small is beautiful, not to mention comfortable.

As of June 2008, I had completed 15 of the 16 doses of chemotherapy that are required for my treatment (four rounds of FEC [5-FU, Epirubicin, and Cytoxan] and 12 rounds of Taxol). I have also had three months of Herceptin infusions combined with the Taxol. After the chemotherapy, I face nine months of treatment with Herceptin, three years of treatment with a drug to prevent bone metastasis and five years of tamoxifen therapy to manage hormone production.

I started to lose my hair on 23 January and by the end of the month was completely bald. This process continued with most of the rest of my body hair. Fortunately, some eyebrow and eyelashes remained. My hair started growing back with the Taxol and I now have a healthy growth of soft stubble on my head.

I will not go into detail about the symptoms of chemotherapy. What I want to share is that overall I have been able to manage surprisingly well. There have been days when, if it was not for being bald, I and those around me would not know I was on chemotherapy. With the help of substantial, but not excessive medication, I have managed with little or no nausea, am seldom tired, eat relatively well, do not feel depressed, have gained only 1-2 kgs and have suffered relatively little in terms of pain and discomfort.

Sometimes, I have trouble concentrating and writing – as though my brain were not able to communicate with my fingers. I have also had to battle with GI problems for the better part of four months, which has proved to be a challenge.

Chemotherapy has induced menopause. It is difficult to know whether the symptoms are worse than they would otherwise have been, and whether they are permanent or temporary. What is certain is that my insomnia is fuelled by them and fed by worry. This turned out to be a difficult part of the treatment process, one that I am only now beginning to internalise. It is a blow to age – in the reproductive sense – the equivalent of 10-15 years in two months.

However, I have gone to work every day, including most of the chemotherapy days. I play with my children and my dogs, and I go out to dinner with my husband. I also managed to visit my mother and pray at my synagogue in Toronto, and to go to Boston for work. On another occasion, I took the second dose of Taxol in Seattle and made a presentation at an international conference three days later. I have run 3-18 kms on my elliptic machine most days. I even exercise immediately after my infusions, although how much depends on how I feel.

I do not mean to imply that this experience has been painless. When I had to face mastectomy, I thought I was mutilating myself. When I woke up from the mastectomy, the pain was so intense that I could not breathe. Further, I was terrified of chemotherapy. So terrified that at first I preferred to face a higher risk of death than have it. My terror came from the fear of seeing someone who looked like a concentration camp inmate when I looked in the mirror.

That said, in April 2008, minus my left breast, my hair and my menstrual cycle – but with a positive attitude and a different outlook on life, a newfound ability to see beauty all around me, and a tremendous sense of pride in myself as a woman – I turned 42.

### How I cope

This phrase has accompanied me since the early days of chemotherapy: while I am not yet a survivor, I am a winner. I think of myself as fortunate, not because I have survived the disease – I have not yet survived the disease, although I have a good chance of doing so – but

because I have gained more than I lost, and feel stronger and better about myself. To each of the challenges thrown at me, I try to respond with an activity that makes me feel more capable or in control than before.

I want to share the first time in my breast cancer experience that I realised how good I feel about myself. Less than three weeks after my mastectomy, in an interview for a documentary, I was asked: "What do you see when you look at yourself in the mirror?" At first, I was silent. In my mind, I saw the image of my body. Then I started smiling, at first to myself and then at the camera, and said: "I see a stronger woman than the one I saw before." This is the reflection that comes back at me, even though in the mirror there is an asymmetric body with a large frown-like scar where once there was a breast, two doorbell-like catheters, an expander and almost no hair from head to toe. Why?

### The family and personal realm

Each day since my diagnosis, I have consciously thought how fortunate I am to have two daughters, that both of them came into my life before the cancer and that we had them when I was able to – Hannah at age 30, when I had just finished my PhD and was re-entering the world of work; and Maha in 2004, when my health (even before the cancer) seemed to make it impossible.

After all the surgery and treatment, it was three-year old Maha's smile that took away the symptoms, much more effectively than medication. Those few times when I felt too ill to be up and about, the only person who could take care of me and make me feel better was 11-year old Hannah, with her secret tea recipe and massage. Having heard of so many women who could not lift their arm after the removal of their lymph nodes, I am especially fortunate because I can take my daughters into my arms and hug them.

I also found ways to share with my daughters the process of living through my cancer. I do not hide from them and they do not hide from me. I answer what they ask, whenever they ask. I show them what they want to see, if and when they want to see it. Often, this has meant reading books and drawing pictures – and some wonderful material, particularly from the American Cancer Society, has made this much easier.<sup>4-6</sup>

Sometimes there is humour. Hannah once asked me for a hairbrush and then we both laughed at why I no longer carried one in my purse. Perhaps my favourite anecdote is about my worst day of hair loss. As large amounts of hair fell into the toilet, generating an enormous hairball, Maha came running in without knocking. I covered my head, but not the toilet bowl. She looked into the toilet and asked: "But Mummy, is your hair falling out from up top or down below?" I didn't know whether to laugh or cry, but since I had already cried for a long time, I decided to laugh. It did me the world of good.

Since my diagnosis, I have been in awe of what has happened between my husband and me. We have been married for 12 years and in fact celebrated, yes celebrated, our 12th anniversary four days after my first operation. After 11 years, as is the case in many marriages, there was a distance between us. Our struggle with breast cancer made it possible for us to rediscover the essence of our relationship, enjoy moments together and for several months, separate ourselves from the day-to-day trials of life and focus on each other. It also put tenderness back into our embraces. Many times over the course of my treatment, I asked myself: "How many women, after 12 years of marriage, can say their husband is once again their boyfriend?"

I have also changed as an individual, in order to cope in a creative way with the physical destruction caused by cancer treatment. First, I consciously appreciate the beauty around me in a way I never could before: the moments when I hear birds singing in the morning, the hummingbirds that sometimes hover on the flowers, the smell of *florifundios*, the times my daughters make me laugh, the foods that I truly enjoy, the intense orange of the roses in full bloom in my garden, and the sunrise I saw with Julio in the hospital after my mastectomy, to name but a few. Now, I register these moments, rather than letting them pass me by, and they remain with me.

I have developed, as I think most cancer patients do, personal coping strategies. First, I search for what I can do better, or at least differently, than before the cancer. Second, I try to manage a sense of normality in my daily life. I also strive to keep a good personal and body image, but one that is attune to living with cancer. In other words, I try to be happy with

what and how I am now, rather than trying to go back to being as I was before the cancer.

Exercise has been surprisingly important. I was not an exercise fiend before, although I did some running and walking. But exercise has now become my way of showing myself that I am not getting sicker, but rather more healthy. It is also one of the best ways at my disposal for controlling nausea, fear, depression, anger and weight gain. I work out in the controlled environment of my home, where I can get on the machine at any time day or night (a good idea with insomnia). Exercise is my way of "sweating out the venom" of the chemotherapy.

For me, continuing daily life in a normal way has been essential. One issue was finding a way to be "presentable", especially for the world of work. While this may not be terribly important for many women, it was for me. So, I developed a new style that allowed me to feel good about how I looked. The old Felicia style had started not to fit – because of the mastectomy, the hair loss and the discomfort of the chemotherapy. Business suits were terribly uncomfortable. My expensive wigs made with my own long hair never fit my face or my head. So, I found my way into head covers and scarves. Next, I realised that what would not change were my eyes, so I worked to make them the focus of my face. Finally, I found low waists, full skirts and open dresses. The point was to find a way to be comfortable with how I looked, to myself and also to the outside world. I never wore a wig for a single day, and many were the times that people who met me did not realise I was bald.

I have tried to avoid being perceived as less capable because I have cancer. For this I have my colleagues, employers and many others to thank. Mostly, I have to thank my friends and collaborators for making it possible for me to work and have cancer, including while I was in hospital. However, I also think my attitude was important. I never hid my cancer, never pretended I would be able to work as I had before, but also never gave anyone the chance not to accept me at work or in public. I have the impression that many cancer patients are either discriminated against, or themselves pull out of daily life. I also have the impression that this happens more frequently with women, perhaps because it is easier for them to be pushed, or fall, out of the world of work.

I have also had the opportunity to convert my personal experience into a motor for generating a programme – *Tómatelo a Pecho* (Take It to Heart) – that has provided a new depth to my work as a health economist and advocate for health rights. The opportunity to look beyond my own experience has also given a new sense of meaning to what I am going through. Each and every operation, chemotherapy, symptom and health problem makes me more and better able to do my work. Thus, my cancer has empowered me professionally and as my work is an integral part of my life and what I believe in, this has translated into empowerment for me.

### As a patient

I count myself as a most fortunate patient. First, I have had access to the best physicians and hospitals in both Mexico and the United States, and insurance coverage to make this possible. The vast majority of women in Mexico living with breast cancer do not have access to high quality health services. Making this possible for more women in Latin America is the goal of my programmatic work.

I live my illness in Mexico as a Canadian citizen and foreign resident. I was diagnosed and I had a mastectomy in Mexico. I am receiving chemotherapy and reconstructing my left breast in Mexico. I am proudly and gratefully a patient of Mexico's health care system. As a result of many years of working on health in Mexico alongside my husband, I enjoy almost 24-hour access to a group of physicians who are also my friends.

At the same time, I have the fortune also to be a patient of the Seattle Cancer Care Alliance with access to the most recent scientific advances in breast cancer treatment and a tremendous degree of patient-empowerment. This has made it possible for me to learn and participate in my treatment decisions. The moments of greatest despair all came at the very beginning when I felt I did not know enough to decide what to do. I remember my first, exploratory appointment with my oncologist in Seattle – only two weeks after my diagnosis. I asked for some reading material and out came two large volumes, including one on exercise and multiple pamphlets on drugs, wigs and other key things I needed to know. Rather than generating more fear, the books in particular helped me to understand

what I would go through. Much less information was available in Mexico and in Spanish. This would later inspire one of the key areas of work of *Tómatelo a Pecho*.

It is often difficult to locate information. Sometimes it isn't easy to understand it or to face what you read. But it is our right and our obligation, as women and as patients, to understand our illness. I also believe that in treatment decisions, active, informed patient participation is key. Often, the patient has to insist with the physician, which may be both frightening and overwhelming. Detailed but straightforward explanations are needed, often followed by time to process and understand them. Knowledge is empowering.

Taking an active role in deciding what my treatment would be made me feel better about the treatment itself. In this process the support of my whole group of physicians was crucial. Although I agonised over the mastectomy for weeks and chose to go through additional surgery first, to remove more tissue in the hope of saving my breast, it proved worthwhile. When the time came for a total mastectomy, I was certain it was the right thing to do and I believe I have suffered much less with the outcome because of this certainty.

The option to reconstruct my left breast gave me the strength to go through with the mastectomy. It helped me to believe I could go back to being as I was before; that the effects of the cancer would not be permanent. It also helped me to face my daughters, as I was worried about looking different as they went through breast development.

With time, my feelings on these points have changed, partially due to the difficulty (I would not say pain) of the expansion process and the multiple operations. Further, my daughters have come to deal naturally with the scar and the absence of a breast, as I have. So, while I have not yet processed everything I feel about breast reconstruction, it is less important for me now, having made the decision to have a mastectomy. However, it was keenly important for me to have the opportunity to reconstruct when faced with a mastectomy.

### Reproductive and sexual health matters

Recently, I have been wondering how I will live with the effects of tamoxifen on hormone pro-

duction. It has taken me eight months to face my biggest fears and the short-term fallout of treatment. There has always been the idea that "everything will go back to normal". Now, I must face what will come back and what will not. What will not improve or go back to normal is related to the parts of my body that defined, for most of life, my sexuality and an important part of my identity as a woman. I will never have feeling in my left breast. Reconstruction is therefore a convenience of dressing, although for many women it may be much more. I may or may not come out of the sudden, chemotherapy-induced menopause, which has many implications and I am still discovering what these are.

### Professional

On the professional front, *Tómatelo a Pecho* has enabled me to channel my personal experience and contribute to the huge effort required to fight breast cancer in Latin America.

About one week after my first surgery, I went for a walk, immersed in feelings of frustration, pain, loss, confusion, and above all, fear. As I walked, I thought about a different scenario – not having access to treatment. For the first time in my 20-year career working on health in developing countries, I could internalise the terror felt by a patient who has to choose between paying for health care or her children's school books. Or, not knowing who would care for her children while she was in hospital. I was torn and sickened by the injustice of my having access to care and her not. So, as I walked, I started to design the project, and to my surprise, I also started to feel less desperate.

I presented the proposal for the project to key members of the board and executives of the CARSO Health Institute in Mexico City the day before my mastectomy.<sup>7</sup> Few activities could have done more to empower me. The proposal was approved with several hundred thousand dollars of initial funding and the possibility to significantly expand, which has since happened.

*Tómatelo a Pecho* focuses on promoting information for patients, families and providers, funding for research, innovation in providing early detection and institutional strengthening. Activities started in Mexico in March 2008 and the initiative is expanding to other parts of Latin America. The need for it has been borne out by

evidence, which is breaking down many of the barriers to care that were based on erroneous or out-of-date facts and figures.

Breast cancer is not a disease only of the developed world. About 45% of all cases and 55% of deaths occur in low-income countries.<sup>8</sup> Further, it is not restricted to older or post-menopausal women. For reasons largely unknown, breast cancer is presenting at younger ages in low-income populations. This may be a “temporary” effect related to demographics or access to health services. Still, a large number of women are being diagnosed before they reach menopause, and breast cancer is often very aggressive in premenopausal women.

Breast cancer represents a huge challenge to women and to the health system in Mexico and other developing countries. In 2006, breast cancer was the second most common cause of death among Mexican women aged 30–54 years. Further, breast cancer mortality rates continue to rise, in contrast to cervical cancer rates, which have been declining since the early 1990s.<sup>9</sup>

In the face of this great challenge, there is an encouraging message: breast cancer is curable if it is detected early. Yet, in Mexico, this message has not yet permeated to patients, basic health care providers or most policymakers. Many women lack information and access to a diagnostic programme performed with respect and dignity. As a result, only some 5–10% of breast cancers are detected early when the probability of cure is much higher.<sup>10</sup> Overcoming these bar-

riers requires action by women as well as the health system.

## Conclusions

What do women with breast cancer see when we look at ourselves in the mirror? I see a mother that can love and hug her daughters as never before. I see a woman whose husband embraces her with more tenderness and affection than when she had two breasts. I see a professional who now brings to her work a depth that she did not have before. I see a stronger woman than the one I saw in the same mirror before breast cancer. I celebrate my newfound strength.

At the beginning of this testimony I wrote: I am a woman, a woman with breast cancer. I thought this was an obvious point when I began my treatment. Now, I am certain that it is not. My identity as a woman permeates my experience. I conclude with this reflection: once the terror and immediate illness of the “cancer” in female breast cancer is overcome, the issue of the “breast” in female breast cancer comes to the fore. Much of what defines being a woman living with breast cancer is precisely being a woman.

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