

PART ONE

# DOUBTING





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CHAPTER 1

## Could it be...?

### Mammogram at 40

In October of 2006, my gynecologist, friend, and colleague gave me medical advice that turned into a gift of life. I still do not know exactly how long this gift will last, but I am now certain that my years of healthy and enjoyable life will not be few.

At my annual check-up, Dilys Walker, who had been my gynecologist for several years, told me that having turned 40, and especially because I had uneven breast tissue,<sup>1</sup> it was time to start getting regular, annual mammograms. As part of the physical examination that I routinely had every year, Dilys carefully performed a thorough clinical examination of my breasts and found no anomaly. After completing the examination, she gave me a written order for a mammogram.

The recommendation to have a mammogram generated in me a mix of lethargy and anxiety. Although I knew of no history of breast cancer in my family and had no reason to suspect a problem, I confess that I was afraid. A routine mammogram is nothing to fear and should not have generated such anxiety. To this day, I have no idea why I was so afraid or if I sensed something was awry.

Since my youth, I have always been very conscientious about getting regular gynecological check-ups and insisting on a complete annual examination with a PAP test. I was obsessive (maybe even extreme), and would schedule an appointment with Dilys at least once a year and, if I could, every six months. If anything alarmed me, any anomaly, any problem, I would turn to her.

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<sup>1</sup>. For more information on the anatomy of the breast see: Love S & Lindsey K. *Dr. Susan Love's Breast Book*, 4<sup>th</sup> ed. Cambridge: Merloyd Lawrence Book-DaCapo Press, 2005.



For some reason, and uncharacteristically for me given how obsessive I am with my check-ups, I decided to hold onto that piece of paper from Dilys' prescription pad for one whole year and postpone the mammogram until just before my next annual check-up. I scheduled the appointment for my first routine mammogram for the last weekend of October 2007. I could never have suspected that for me this would be my first and last 'routine' mammogram.

I do not know if it made any difference that I delayed for a few months; in fact, it may have been a good thing, making it easier to identify suspicious images that perhaps would have gone undetected a year earlier.

What I do know is that I had enough training not to delay the mammogram too long. At the time, I had already accumulated two decades of experience working on health system reform in Latin America and globally. I studied health and development economics and have a doctorate in Economics from Harvard University. One of my areas of expertise is women's health. I also married into health. Dr. Julio Frenk Mora, my husband, held the position of federal Minister of Health of Mexico during the administration of President Vicente Fox, from December 2000 to November 2006.

Yet, in delaying my mammogram, I reacted as many women do and it is important to understand why I did. Women experience tremendous fear about mammography. Consequently, we tend to avoid having a mammogram despite the fact that it is, without a doubt, the best way to protect ourselves from breast cancer.

The tendency to avoid mammography is even greater if women have reason to suspect that the images will not be undertaken properly or interpreted correctly, that the results will not reach them, or that the test will not be administered in a respectful and dignified fashion. I later found out, as I heard the experiences of many women in Mexico and other developing countries, that a high-quality mammogram undertaken in a respectful manner—like the one I could fully expect to receive—is far from the norm. All too often, and especially for poor women and in lower-income countries, gaining access to effective mammography is a huge challenge.



In personal testimonies, women continue to share with me how they were left undressed for long periods of time, waiting in line to get a mammogram without any explanation about the test or why it is important, and then waiting several weeks or even months to obtain their results. Although there are several government programs and civil society organizations working to improve access to high-quality mammography in Mexico, it continues to be true that only a minority of women have the luxury I had: to decide when and where to have my baseline mammogram.<sup>2</sup>

In too many countries, even when women are screened or find a lump in their breast and seek medical care, they encounter a resistant and even hostile health system. Too many women with late-stage breast cancer have described to me how a physician insisted that a mammogram was unnecessary and that they were overreacting.<sup>3</sup>

The lack of responsiveness of the health care system is symptomatic of and exacerbates the gender discrimination these women probably face every day at home, at work, and in their communities, especially if they are poor. It is part of the stigma they will confront living with breast cancer, a disease directly related to their physical identity as women and to their reproductive health.<sup>4</sup> I grew to understand this better when I began to try to teach low-income women in Mexico about the importance of regular mammograms. Many women, especially those who are poor, tell me they will refuse any type of screening mammogram because they are afraid of being abandoned if their partner thinks something is medically wrong with their breast.

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2. Nigenda G, Caballero M, & González-Robledo LM. Barreras de acceso al diagnóstico temprano del cáncer de mama en el Distrito Federal y en Oaxaca. *Salud Pública de México* 2009; 51 (supl. 2): S254-S262.

3. In response, *Tómalo a Pecho* developed a training program with the National Institute of Public Health of Mexico supported by the Seguro Popular that is working with health promoters, nurses and physicians in several states. <http://tomaloapecho.org.mx/>.

4. Knaul FM, Gralew R, Atun R, Bhadelia A. *Closing the Cancer Divide: An Equity Imperative*. Based on the work of the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries. Cambridge, MA: Harvard Global Equity Initiative, 2012. Distributed by Harvard University Press.



Thus, my situation was very privileged compared to that of the majority of women living in Mexico. It would take months for me to recognize it, but I was lucky.

## **The mammogram and the precipice**

Nothing foretells news that will transform your life. Nothing around you suggests that the morrow will be different, and that your life will take a radical turn for the worse. October 27, 2007, was a Saturday like any other.

Like many women, I juggle the difficult balance between the roles of wife, mother, daughter, sister, and professional, as well as having my own hobbies and interests. My face often reflects the stress and my eyes the desire, to double, triple, and quadruple myself so as not to face the frequent dilemma of being in one place while wanting or needing to also be in another.

That Saturday in October was no exception. The appointment for the mammogram was at 10:30 in the morning. My daughters, Hannah and Maha, had swimming and art lessons at home. I also had a meeting scheduled with my colleague, Gustavo Nigenda, who was coming over to the house with his two-year-old daughter.

Unfortunately, my mammography session was running over the allotted time because the technician insisted on taking extra images. This made me very nervous and worried. I had already put my shirt back on in order to quickly leave the doctor's office when the radiology technician came into the cubicle and shook me abruptly out of my thoughts. "Please undress again. We have to repeat some images."

"I'm running very late," I thought. "I should have called Gustavo to tell him we should meet at 11:15 instead of 11:00." I was frustrated and worried about the time spent on this routine medical procedure, one that I had assumed would take no more than 20 minutes. The concern about being late for my meeting, in fact, helped me by diverting my attention from the anxiety and fears that were growing as the number of images increased.



After taking several additional films, the technician asked me not to get dressed again because the radiologist would probably want more tests. My frustration mounted as I realized that I had spent much more time than expected at the clinic. The technician showed me out of the booth and sat me on a bench, still in the gown. I insisted that I had to leave, and she told me that the radiologist wanted to do an ultrasound.

I was alone, waiting outside the room where only minutes before I had my baseline mammogram. I did not want to spend any more time on a ‘routine’ examination, so I decided to call Dilys. I was already running very late, and somebody had to help me get out of that clinic.

“Dilys? So glad you answered your phone. I came to have that routine mammogram you asked for, but I am running really late. Gustavo is waiting for me at the house. Can you help get me out of here? Could you tell the doctor to let me go now? It always happens, but please tell them not to do anything special, you know, because I’m Julio’s wife.”

I asked the radiologist to please speak with Dilys –they knew each other– and handed him the phone. As I did this, I glanced over into his office where the images of my breasts were up on a backlit screen. Since I had never seen a mammogram before, I did not know there was anything abnormal or worrisome about some little dots of light that I saw near the nipple in one of the images.

There was a pause in the phone conversation. Time seemed to be passing more slowly. I became very uncomfortable. The rhythms of my surroundings had changed. I worried. “Why is Dilys talking to the doctor for so long?!” I bitterly complained to myself with a sense of frustration that quickly mutated into a dark cloud of fear and apprehension.

I began to think about all the times I had tried to do breast self-examination. Since my breast tissue was dense and irregular, every attempt left me feeling very anxious. To my ill-trained hand, all the tissue felt full of small, worrisome lumps. Those experiences were similar to the unpleasant anxiety assailing me at that moment in the clinic.



I remembered how, when I was about 20 and just a few years after my father's death from cancer, I was convinced that I had found a small, suspicious lump in one of my breasts. Extremely distressed, I immediately called my best friend, Renata Block. She, a woman much older than I, was the social worker who accompanied my family through my father's battle with cancer. Renata, who herself succumbed to cancer in 2004, was a person in whom I confided many things.

On that occasion in my early twenties, I went to see my gynecologist and found that there was absolutely nothing abnormal. That time, it was just me overreacting. This time, I could not call Renata and my thoughts turned to how much I missed my dear friend, as I still do, and to how all my losses of those closest to me had been to cancer.

I could not manage these thoughts. I realized that I would drive myself to panic. I forced myself to contain my mind firmly in the fear of the present.

I tried to calm myself down by thinking that I always exaggerate things; that this time was no different than when I was in my twenties. I went back and forth between chastising and consoling myself. "You've done everything right and you are only 41 years old. Aren't you still young? Of course you are. And this is a routine examination. You're a hypochondriac. You're a hyper-chondriac. You are a *super*-chondriac! There can't be anything wrong. That's why you always went to the doctor regularly. Because you had a lot of lumps and you were always scared when you touched your breasts trying to find something. So, of course, it's another cyst..."

The ideas were accumulating like drops of rain in a storm, one after another, while the seconds passed. Just as in a heavy downpour, they threatened to overflow the barriers that are built to contain them.

Suddenly, I remembered that my physicians had advised me to look for changes when I explored my breasts. I began to think about this and resumed the conversation with myself. "OK, let's remember if you noticed any change since your last appointment with Dilys. There was some dryness in the last few months, but this time it was a little different: over the areola and only on the left side.





But you went for a breast examination just a year ago and there was nothing,” I reminded myself. “The radiologist still hasn’t told you what they are seeing on your mammogram. Maybe they’re looking at the right side. Felicia, you are exaggerating,” I rationalized in silence, in a frenetic and useless effort to calm myself down.

Barely a few minutes had passed, maybe five, but it felt like eons of time had gone by. Something significant had changed. Nothing seemed routine anymore. Yet, and perhaps for the first time in my life, I simply wanted to be normal and typical instead of special or exceptional.

The radiologist handed back my phone. An awful wave of nausea came into the back of my throat, and spread down my esophagus, heading towards my stomach. I had a premonition that something very unpleasant was on the way. I perceived a worry that I did not want to hear in the tone of Dilys’ voice. Instead of lifting the dark cloud of doubt and fear, the cloud grew darker. “Felicia, let them do everything they think is necessary. I’ll see you afterwards here in my office. Bring your mammography films.” There were no more questions for me to pose. Dilys had said it all.

I suddenly realized that I would never arrive at the appointment with Gustavo at my house. In a matter of seconds, all else that was supposed to have happened that morning faded into the background. It all seemed part of another life, a life of normalcy so different from the one I was now being forced to enter. I teetered between realities –healthy versus diseased, routine versus chaotic– and began to lose touch with both. One was the life that I continued to try to hold onto, but that was quickly slipping away from me; the other was a new life, a new world, that I desperately tried to reject as not happening to me. I attempted to cope by trying to envisage the scene from outside of myself, as a spectator.

At the same time, I clutched onto simpler matters as a means of coping. I called Gustavo at the house and told him that there was a problem with the mammogram. To prevent myself from bursting into tears, I refused to go into any detail, despite his insistence. I told him to please make himself at home and start working; I would get there as soon as I could. I asked him not to say anything to the girls, and to have Maha play with Sofi as if nothing out of the ordinary was happening.



Despite my best efforts, I was not very successful at diverting my thoughts. I was thinking about so many things that I did not want to think about anymore. Worse yet, I did not really know *what* to think. I had no information. I remember it as the first moment of absolute terror fueled by uncertainty – perhaps the worst kind, as it is the fear of the unknown. The panic fed on itself and became increasingly profound and overwhelming, yet I could not show or release it because I was sitting in a clinic surrounded by strangers.

I continued to have the impression that I was my own spectator, watching from somewhere outside of myself. I struggled with an overwhelming feeling of vulnerability that was beginning to consume me. I saw myself as small and frail, naked from the waist up except for a gown that barely covered me, in the hallway of a health clinic, surrounded by a huge cloud of fear and uncertainty. This cloud was enveloping me, threatening to invade and take over the space where a healthy, determined woman had been only a few moments before. A cold sweat trickled down my back. And then the tears of fear finally started to pour out.

This was not the only time I would observe myself and judge my state of being as if I were a bystander. It was merely the first time.

Indeed, as I reread this book almost five years after those first, terrifying moments of learning to know my cancer, I am struck by the contrast of how I saw myself then compared to now. My first images of myself are as a frail and weak spectator. Now I perceive myself as a strong and stable person who wrestles with the disease. I am proud and grateful that I was able to heal from the inside out.

Yet, I still recall and can describe the feelings and sensations of those first moments. It was like falling off a precipice into an abyss, without knowing how the fall happened or how the firm ground that moments before had sustained me had suddenly disappeared from under my feet. I knew not where I found myself, nor the depth of the abyss into which I was falling. I had no sense of when I would reach the bottom, nor what I would find there. I could not fathom how, or if, I could escape from the hole I was falling into. As the hole grew deeper, I realized I had no idea what



tools I would have at my disposal for the long climb out, or where to look for escape routes. And as I fell, I feared never again feeling firm ground. Indeed, I had no sense of when I would hit bottom, or if, once I did, I would ever get back to the point from which I had fallen. In a tiny span of time, I had totally lost my bearings and had become utterly confused.

The sensations of falling off a precipice and plunging into an abyss continued for the next nine days. There were few moments of respite. For me, these days were my first encounter with the uncertain and the unknown, a shadow that today, however faint, I know will accompany me for the rest of my life.

The depth of this sense of uncertainty took me completely by surprise. It was the first of what would become many encounters, as I gradually accustomed myself to living with the fear of a disease – a new, uncomfortable, and unwelcome companion that is a part of the daily existence of those of us who live with a chronic and potentially lethal illness. Indeed, learning to make peace with the fear that the disease could recur is an essential part of survivorship, at least in my case.

To manage to live with the specter of uncertainty, I eventually developed a set of coping skills and strategies. The first was to *compartmentalize* my feelings. I packed my fears away into separate boxes, to be opened when, as, and if I found the emotional and physical tools to confront each one. If it were not for these coping mechanisms, I would face the specter every day with the same level of unbearable anguish that I describe above, and which at first threatened to overwhelm me.

Unfortunately, at that moment I was bereft of coping strategies and had no idea of how to package away my fear.



## What is a BI-RADS?<sup>5</sup>

The radiology technician guided me to another room for the ultrasound. As the radiologist came out of his office, I looked straight at him for the first time. I was calmer now, and I wanted to get very clear answers about what was happening to me.

“I just found out who you are married to,” said the radiologist, “but, only because Dr. Dilys<sup>6</sup> told me. Before her call, we had no idea. I want you to know that none of the tests we are doing are because Dr. Julio Frenk is your husband.”

And then he uttered the words that I still remember to this day, because with them I lost hold of that tiny space of solid ground onto which I had retreated, fell off the precipice and was catapulted into the abyss: “We are doing all this because there is a suspicious image, and we think you have a problem.”

“What side is the suspicious image on?” I asked him. “The left,” he answered. I remembered the secretion, and that I had gotten a bit scared when I noticed it months ago, but thought it was just dryness of the skin.

More terrible thoughts began to chase away the previous ones. I realized the nightmare was going from bad to worse and that I was wide awake. I started to cry from the fear, but quietly and just a little. I also cried at the paradox of standing before a man that I had never seen before, and who was now giving me such brutal news that would forever mark my life. The four words ‘you have a problem’ quickly became five in my mind: ‘You have a serious problem’.

While he was performing the ultrasound, the radiologist mentioned something about ‘bye rad’. I had no idea to what he was referring. I had never heard the term before. Later I learned BI-RADS<sup>7</sup> is a way of grading tumors, and that my grade provided

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5. Love S & Lindsey K, 2005.

6. In some parts of Latin America it is not uncommon to refer to a professional using their title and first name.

7. BI-RADS stands for Breast Imaging Reporting and Data System. See: <http://www.acr.org/Quality-Safety/Resources/BIRADS> for additional information on this much-used system for grading the severity of tumors.



sufficient reason to be very concerned. Very fortunately for me, this radiologist knew how to read a mammogram properly. He graded the image correctly—as highly suspicious—and sounded the alarm.

I would grow to feel much more afflicted by the BI-RADS term over the nine long days that followed, while awaiting the results of the biopsy.

It took me months to appreciate how fortunate I was to have been blessed with a relatively early diagnosis. An erroneous mammogram can literally be a death sentence, as it means losing precious time to a tardy diagnosis of the disease. Diagnosed early and treated, five-year breast cancer survival is today close to 99 percent. Yet, timely diagnosis is the exception rather than the norm in most parts of the world. The majority of women diagnosed with breast cancer in low- and even middle-income countries are in very late stages.<sup>8</sup> Diagnosed late, even with appropriate and sufficient treatment, the probability of survival falls to below 25 percent.<sup>9</sup>

Indeed, there are few—maybe even very few—radiologists specialized in breast imaging in Mexico. I would remember this moment 12 months later, sitting in a public event of the *Asociación Mexicana de Mastología* (Mexican Association of Mastology), when I learned about the case of a woman whose breast cancer took eight years to diagnose. It was delayed not because she did not get her mammograms, but because they were interpreted incorrectly. I saw pictures of eight years of misinterpreted (or perhaps never interpreted) mammograms and a final diagnosis of invasive and advanced breast cancer with little hope of survival for the patient.

That October 27, completely ignorant of my fortune, I asked the radiologist, “Doctor, what does ‘bye rad’ mean?” He answered: “A BI-RADS of three to four is a mammography that suggests a high probability of a malignant lesion.” I insisted: “How high is the probability?” My voice trembled, and I repeated *howhowhowhow* or

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8. Shulman LN, Willett W, Sievers A & Knaul FM. Breast cancer in developing countries: Opportunities for improved survival. *Journal of Oncology* 2010. Article ID 595167.

9. American Cancer Society. Breast cancer facts and figures 2011-2012. Available at: <http://www.cancer.org/Research/CancerFactsFigures/BreastCancerFactsFigures/breast-cancer-facts-and-figures-2011-2012>.



maybe *hhhhhow*. He answered, an unwelcome reply, “More than 50 percent. Perhaps 60.”

The radiologist marked and measured a lesion of 1-2 centimeters with the ultrasound device. The fear began to escalate and I thought I could hear it drilling a hole in my mind. Or perhaps it was my heart that I heard, now beating hard and rapidly. In front of my face, I saw a stain, a shadow, on the ultrasound screen. It was the mutilation produced by my *altered-self*—the term I would come to use to refer to my cancer.

I recall that the image of the breast lesion made me think of how, once before, I had seen a small spot on an ultrasound screen. That time was my first and only full-term pregnancy. The spot was the first photo we have of Hannah. The irony made the tears flow.

The words were booming in my head. “Probability of what? Of having something? What *something?*”

I suddenly understood. Heavy words fell down on me... “Of having a malignant tumor. Of having cancer.”

Once again I broke into a cold sweat, and my legs trembled as I realized the magnitude of the problem. The bad news I was hearing was about my body. I struggled to understand and asked myself incredulously, “How did I get to this point? How did this happen? What did I not see? I could not feel anything. There was no change in the skin of the breast. Just that little bit of dryness, but that was surely nothing.”

As I dressed, in my head, in my mind, I could not stop questioning and thinking about different scenarios. I was trying to understand what the probability really was of having cancer. Yet, I had very little understanding of my situation. I did not know the meaning of the technical or medical terminology. The information I had received was overwhelming. Yet at the same time, it was too little information. Contradictory, yet true. I knew I had a suspicious BI-RADS, a key piece of data that could mean pain, suffering, and death. Yet, this was only a tiny fragment of the complex information that would be needed to actually diagnose ‘the problem’.



When I called Dilys again, she said, “Felicia, come to my office immediately.” Once again, I perceived that ominous tone in her voice. I sensed that something catastrophic was happening to me.

By this point, I could not stop crying despite my best efforts to control myself.

Again I took refuge in everyday matters. I thanked the radiologist and asked him to forgive me for having resisted doing the ultrasound.

I would meet both the radiologist and the technician who had read my mammogram again, though several years later and in a very different setting. I was invited to speak to a group of women, many of whom were facing breast cancer, at the *Hospital de la Mujer* (Hospital for Women) in Yautepec, Morelos. This is a public facility located about one hour, by car, from the clinic where I was diagnosed. I was taken on a tour of the hospital that began with the mammography suite, because the hospital and the Ministry of Health of Morelos are striving to put in place better screening and diagnostic facilities for breast cancer. As I stared at the face of the radiology technician who came out to proudly show me the quality of the services being offered to low-income Mexican women, I realized that I recognized her from somewhere. But I could not understand why this brought a wave of terror over me. As I heard her speak and watched her facial expressions, I realized she was the same woman who had insisted and convinced me to have additional images taken of my breast in 2007. I made her recall my case and later that same day, I met my radiologist who was now also working at the public hospital. I share this story whenever I can. I am grateful that at least some women in Morelos have access to the same quality mammogram that I did. I continue to dedicate myself to making this the rule rather than the exception.



## **I am not overreacting**

I do not remember how I physically left the clinic. How does one walk? What are on-lookers thinking or what do they say to you? What tone of voice do people use to say good-bye and step aside to let you leave, knowing you are so upset?

I remember closing the door of the clinic and finding myself facing the passers-by on the street, with tears on my cheeks. I stood on the sidewalk and the tears flowed freely. I did not care that people would see me. I called Gustavo and tried to calmly explain to him what was happening as I paced from side to side in front of the clinic. I asked him to act normally in front of my daughters.

I also told Leticia Rivera, our girls' art teacher, and I asked her not to say anything to Hannah about the mammogram because there was still no confirmation that there was a problem. I only hoped that Hannah, my intelligent and perceptive daughter, would not suspect something out of the ordinary had happened.

I did not want to frighten the girls. I myself was terrified enough.

I thought about how and when to tell Julio. My heart sank because I feared an indifferent reaction from him as a reflection of how I had often been overly worried about my health issues. At any rate, he was on his way back from a meeting in Geneva at the World Health Organization and I would not be able to speak to him until he reached his stopover in Madrid. I realized that was a good thing, because I could not talk to him until after I saw Dilys. I was sure I would be calmer and better informed after seeing her.

In the 15 or 20 minutes of travel between the clinic and Dilys' office, I calmed down a bit. I could not allow myself to become hysterical in the car. Indeed, there are times when one must act normally and calmly, even though everything inside and around you is chaos. Once again, I was learning to use everyday life as an anchor to control my emotions.

I finally arrived at Dilys' office. She was with another patient. The wait was longer than expected and those few minutes became hell for me. To stay calm, I walked from one side of the





waiting room to the other, but eventually this stopped helping. I began to feel that I was losing control of my emotions, so I quickly picked up some brochures to distract myself.

Unfortunately, I grabbed a brochure about cervical cancer that was on the receptionist's desk. Looking at the pictures, I realized that, despite having used the word cancer many times, despite being at my father's side when he died of stomach cancer, and despite accompanying my best friend Renata a few days before her death from thyroid cancer, I had never seen a photograph *of* cancer. I had never looked at a malignant tumor. The photos in the brochure changed that. I saw invaded tissue and I realized how the cancer grows and takes control of one's body, penetrating healthy organs. My eyes filled with tears and the repulsion rapidly converted itself into terror as I stared at the whitish tumor masses penetrating previously healthy tissue.

When Dilys opened the office door, she took me in her arms. "You have reason to cry," she said. I realized that even though we were friends, we had never embraced like that before. She is very tall and I reach the level of her shoulder. In fact, I fit under her armpit like a young bird in the wing of one that is fully grown.

I tried to unload everything I was feeling on her at that moment, but I could not cry because I was so terrified. The fear, almost like an anesthetic, had paralyzed me.

Dilys looked at the images and examined my breasts. She explained that the tissue where the tumor was thought to be located felt very hard, and what she was feeling was not present the year before. She gave me a different probability than the radiologist—"70 percent"—and pronounced the words with a look of outright concern.

Dilys was, and has always been, completely honest with me. She has been a pivotal source of support throughout my ordeal with cancer. Dilys never tried to make me believe that things were better than they were.

I asked for her opinion about what to say to Julio. She answered: "Tell him that I said that this time, for the first time since I have known you, you are not exaggerating; that this is not you



overreacting. You need to tell him that this is likely to be serious; that the image is very suspicious.” This was one of the moments – and there would be many more to come– when time stopped. It was the moment I realized that I truly had, not a serious problem, but a very serious one.

We began to discuss the next steps, to plan what to do and with whom. I was anxious to resolve everything about where to go for treatment, what doctor to talk to, and when to do so. The first issue was where to go for the biopsy and who would perform it. Although I did not understand this at the time, eventually I would have to decide how and where the surgery would take place and with which surgeon, who might also be the person who did the biopsy. I remember this as the first ‘decision-making moment’. I had no idea that it was the first of many that I would face, each one more difficult and anxiety-provoking than the last.

Months later, when I began to read the testimonies of other women who lived through breast cancer,<sup>10</sup> I realized that my experience and anxiety with decision-making were not unique. Cancer brings with it a tangled storm of decision-making that generates a chain of perpetual anguish.

Dilys and I talked about medical insurance. I was not sure I was completely covered and that created a new source of distress: how to finance what was coming. Several days later, I found out that I had the tremendous good fortune –thanks to my husband’s work and a wise and generous decision of a friend at the Bill & Melinda Gates Foundation– to have medical insurance that covered me in Mexico as well as in the United States.

In hindsight, I am aware of how very important it was for me to experience this moment of additional anguish related to the financial aspects of my treatment. It made me understand, if only for a few days, what millions of people diagnosed with a significant health problem suffer when they lack financial protection for their health care.

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<sup>10</sup> Shapiro M. *Life in the Balance: My Journey with Breast Cancer*. Toronto: Harper Collins Publishers, 2006; and Marchetto MA. *Cancer Vixen: A True Story*. New York: Alfred A. Knopf, 2006.



Until that moment, my almost two decades of work on health financing in developing countries and in support of the development of *Seguro Popular*<sup>11</sup> in Mexico had been an analytical, arm's length experience.<sup>12</sup> My work had been done from the desk of a health economist and as a policy advisor. It was always from the comfortable position of tackling a problem –the lack of financial protection in health faced by billions of people around the world– that had never affected me directly. The distress of being unable to afford health care or having to deprive your family of things they need in order to be able to pay for your health, only comes to life when you experience it in the flesh, as a patient.

It is not the same to learn about a health system as it is to live in one. Some three years later, Julio summarized his experience as a caregiver accompanying me through the disease, compared to his time as Minister of Health of Mexico: “It is not the same to live as to lead a health system.” A few weeks after my diagnosis, this awareness would be transformed into a source of inspiration to develop a program that eventually led to the birth of a civil society organization, a global task force, and a line of research.

Dilys and I decided to first call my sister-in-law, Alicia, a doctor of great prestige in Mexico who would become another pivotal source of support in facing my health dilemmas. After dialing a few times, I managed to get through to Alicia but I quickly passed the phone to Dilys so she could explain the situation. She shared what information we had and impressed upon Alicia the apparent

11. *Seguro Popular* was created through a major reform of the Mexican health system, undertaken in 2004 when my husband was Minister of Health, to provide financial protection for health care to all Mexicans who lacked access to social security. In 2012, the country achieved universal health coverage. Knaul FM, González Pier E, Gómez Dantes O, et al. The quest for universal health coverage: achieving social protection for all in Mexico. *The Lancet* 2012; 380(9849): 1259-1279.

12. Knaul FM, Arreola-Ornelas H, Méndez-Carniado O, et al. Evidence is good for your health system: policy reform to remedy catastrophic and impoverishing health spending in Mexico. *The Lancet* 2006; 368(9549): 1828-1841; Frenk J, González-Pier E, Gómez-Dántes O, Lezana MA & Knaul FM. Comprehensive reform to improve health system performance in Mexico. *The Lancet* 2006; 368(9546):1524-1534; Knaul F & Frenk J. Health Insurance in Mexico: Achieving Universal Coverage Through Structural Reform. *Health Affairs* 2005; 2: 1467-76; Seguro Popular de Salud. <http://www.salud.gob.mx/unidades/dgpfs/jaq.htm>.



severity of my case. These two women –doctors, confidants, dear friends, and, in the case of Alicia, family– then discussed my body and my health in ways that made me tremble and at the same time feel some security and comfort. They began to work through what would be a very long process of next steps to take, beginning with the selection of a surgeon and the biopsy.

I desperately wanted to convince myself that this was not happening to me; that Dilys was speaking to Alicia about someone else; that they could not be talking about me. But the constant shadow of catastrophe was already, and at the time I thought permanently and irreparably, looming over my life. I was beginning to internalize how this phantom would accompany me for a very long time. Moreover, I started to again notice that everything was happening as if reality was taking place outside of me. Felicia, the person they were discussing in such great detail, was merely a spectator to the show. It was not a comfortable feeling, but I found it equally uncomfortable, if not more so, to be ‘present in the present’.

By the time it was my turn to speak to Alicia, I was very agitated. She had to be tough to contain me, which I remember angered me at the time, but for which I am now very grateful. Quickly and confidently, she proposed a surgeon, Rubén Cortés, who operates at the Médica Sur Hospital<sup>13</sup> and in the *Instituto Nacional de Ciencias Médicas y Nutrición Salvador Subirán* (National Institute of Medical Sciences and Nutrition),<sup>14</sup> where Alicia heads the outpatient department.

Alicia reminded me that Rubén had operated on me two years prior when a lump appeared on my neck. That lump turned out to be nothing more than an infection and, of course, an over-reaction on my part. At that moment, I remembered how afraid I had been of that little lump in my neck, which ended up being benign. The memory of the neck operation did not help, because I thought to myself, with a worrisome mixture of certainty and uncertainty, that this time, the little ball was of a different magnitude and another type.

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<sup>13</sup> See: <http://www.medicasur.com.mx>.

<sup>14</sup> See: <http://www.innsz.mx/opencms/index.html>.



I changed the tone of the conversation by consulting Alicia about one of my major concerns of the morning, a concern that to others might have seemed trivial: our long-dreamed-of vacation to Disneyland. Julio and I had put so much time and effort into planning the trip for our two daughters, Hannah and Mariana.<sup>15</sup> Maha was three and would be going for the first time. Our departure date was in four days. Alicia immediately took up the battle of convincing me not to forfeit that opportunity, because nothing would change in a week. This conversation would continue for days and keep us both busily thinking about something other than the future of my health.

After speaking with Alicia, Dilys and I decided to look for Misael Uribe, who had been my gastroenterologist for many years and also the president of *Hospital Médica Sur*. Misael gave me the same recommendation as Alicia: Rubén Cortés. He also offered to try to contact Rubén so that I could see him as soon as possible – on Monday. I remember thinking: “Monday is the day after tomorrow and I cannot possibly be ready for surgery the day after tomorrow because I have so many other things to do...” Yet at the same time, and in stark juxtaposition, I was tortured by facing what seemed an eternity: to wait 48 hours for more information and clarity about my situation.

## **Tell me I *am* overreacting!**

Finally, back in the car, heading home, sad and more exhausted than distressed, I was able to reach Julio. He had just arrived in Madrid and was awaiting his flight back to Mexico. As soon as I heard his voice on the phone, I realized that I would have preferred that he had not answered my call. For a brief second, I had the inkling to just hang up and pretend to us both that nothing was

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<sup>15</sup> Mariana Havivah is Maha for me. First because a Maha is a beautiful woman in Spanish; and second, because my pronunciation in Spanish of Mariana is embarrassing to us both.



wrong. I kept thinking that he would dismiss what I was going to tell him as unimportant.

I repeated Dilys' exact words: "Dilys asked me to tell you that this time I am not exaggerating." And I went on: "Julio... I think I have a serious problem..." I proceeded to try to explain everything that had happened in barely three hours: the mammogram, the ultrasound, and the conversation with Dilys.

Looking back over the months and years of my life with cancer, I realize how fortunate I am to have Julio as my partner. The only rejection that I ever had to fear from him was denial of the initial diagnosis. In an interview for *Science*,<sup>16</sup> more than three years after my diagnosis, a reporter asked me about this precise point – had I ever felt rejected by my partner, by Julio. I thought through all the months and years of life with the disease and answered him with conviction, "Never." I also realized and shared that I was unsure if I could have done for Julio what he has done for me. To be a caregiver for a person with cancer takes strength of character and commitment that I hope are never tested. I pray that our roles are never reversed.

I highlight the importance of Julio's commitment because it is strikingly different from what so many other women with breast cancer experience from their partners. In fact, it was Julio who insightfully wrote that stigma, discrimination and machismo are the social cancers that prevent women from seeking health care and diagnosing breast cancer early enough to make treatment effective.<sup>17</sup>

I recall that when I shared the news with Julio for the first time, I wanted him to dismiss my fears and tell me that I was wasting his time. I wanted to hear that the mammography results were not important and that I was, once again, overreacting. This time I really wanted it to be different – I was still hoping that I *was* overreacting.

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<sup>16</sup> Enserink M. A push to fight cancer in the developing world. *Science* 2011; 331(6024): 1548-1550.

<sup>17</sup> Frenk J. Awareness, early detection, and combating prejudices: Keys to fighting breast cancer. *Salud Pública de México* 2009; 51 (Suppl.2).



By that time, it was almost two in the afternoon. Julio reserved his judgment about the gravity of the situation. We agreed that the next step would be for him to talk to Dilys, and I gave him her phone number.

I waited in the car. Julio called me back almost immediately and said in a calm tone of voice that I found hard to believe because he reduced the probability of malignancy from what Dilys had told me: “Dilys told me 50 percent.”

A long conversation ensued, between Madrid and Cuernavaca, about what to do next. This was much more worrying. Julio hates to talk on the phone. Yet, this time he was not using his typical voice of total frustration (which angers me so much), the voice he reserves for when I keep him on the phone, especially on an expensive international call.

I remember that I stayed in the car, parked outside the house, to talk to my husband. I continued the conversation there because I did not want the girls to find out what was going on. In fact, I remember exactly where and how I was seated during that telephone conversation; again as if it were a movie and I was a spectator rather than the main character.

We came to the topic of our trip to Disneyland, and Julio said that we were obviously going to cancel. I remember how vehemently I answered him: “Absolutely not!” In that instant I began to sob, and gave him the best and most hard-hitting reason for not cancelling, truly a reason so powerful that it scared me to say it to him: “Julio, it may be the last time that I can take my daughters on vacation.” I remember that at first he did not answer. There was a brief silence. Then he said to me, with affection in his voice, that I should please not worry about the trip. That we would go to Disneyland.

Julio also said that he was going to start making phone calls to physicians and friends. This was the confirmation of what I already knew to be true: things were bad, perhaps very bad.

Julio spent the next four hours on the phone while he awaited the flight that would bring him to Mexico the next morning. He spoke to Alicia and to Misael, and they were both trying to



contact Rubén, who was turning into a focal point for me. I, in the meantime, was in our house awaiting Ruben's call and at the same time, fearing the moment I would hear his voice.

Julio telephoned me repeatedly to give me news. I remember that he spoke to me very affectionately and that I would still have preferred to hear the typical note of frustration for unnecessary international calling from Europe. It was another sign that things were looking bad for me.

It was not until eight months later that Julio shared his memory of those disturbing hours in the Madrid airport. We were on our way back from a vacation in Europe to celebrate the end of 16 rounds of chemotherapy and we stopped at the same lounge. He showed me the table and the chair where he had sat for hours, with his own level of anxiety ever increasing, making phone calls to try to ensure and organize the medical care he was certain we would need.

## **Next steps; first decision**

After ending the first round of calls with Julio, I remained seated in the car in front of the house. It was clear to me that I could not go inside to greet the girls with the fear and panic that were eating me up inside and were surely reflected in my face. I am basically a rational woman, and at that moment I needed to preserve that feature of my character in order to calm myself and protect my daughters.

I was exhausted. My mental and emotional stability had been disrupted in a matter of hours. I had a wealth of questions and a dearth of information. Yet, I tried to set those thoughts aside in order to determine how to initiate a process that I did not know how to begin. What I remember most are the repeated and combined sensations of terror and doubt, fueled by the lack of information and clarity around my situation.





Somehow, and for the first time, I realized that my greatest fear was of the chemotherapy, but I had no inkling as to why. Sitting in the car I kept thinking and saying over and over to myself, “I would rather die than go through chemotherapy.” The fear just hovered around me, mixed and muted with the uncertainty of a partial diagnosis. I could not yet fathom how both the Nazi concentration camps<sup>18</sup> and my father’s experience were bound up with my own fear of cancer and chemotherapy.

I do not know how long I sat in the car, waiting to calm down before going into the house. I also cannot remember how I got out of the car, because I know I was shaking and my legs were jelly-like. What I do recall is watching myself, once again like a spectator, walking along the garden path and up the steps towards our dining table. Reality hit when my little one, Maha, came running towards me to give me one of her full-body leg-hugs.

Next I saw Hannah, then 11 years old. She nonchalantly said that Leti had told her everything. Fortunately, the only thing I thought of asking her was, “What is *everything*?” She explained that she knew I had had problems with my medical exam. I realized, from the matter-of-factness with which she was speaking, that she either had not grasped the seriousness of the situation or did not yet want to understand it. Either way, Hannah was making use of a wonderful tool that tends to be highly developed in children: to take in no more than what they can and need to assimilate.

At that moment, I made my first truly important decision, one that determined many that would follow. I suddenly remembered with absolute clarity my own anger and terror when I realized that my father’s cancer was much more advanced than what his doctors had led us to believe. With this memory in mind, I decided

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<sup>18</sup>. For more information on Nazi concentration camps and the Holocaust, the mass murder of six million Jews by the Nazis during World War II, see: Museum of Jewish Heritage, A living memorial to the Holocaust, <http://www.mjhnyc.org/findex.html#.UGLdsmgW34c>; Yad Vashem <http://www1.yadvashem.org/yv/en/holocaust/about/index.asp>; Gutman I, editor-in-chief. *Encyclopedia of the Holocaust*. New York: Macmillan, 1990. 4 volumes; Rozett R & Spector S. *Encyclopedia of the Holocaust*. Jerusalem: Yad Vashem with Facts On File in the United States, 2000. Available at: <http://secure.yadvashem.org/store/product.asp?productid=319>.



that, come what may, I would seek to protect my daughters from fear, anguish, and anxiety, but not from the truth. I had to be honest and open with them, as I had asked the physicians and my parents to be with me when my father became ill. I knew with a strong sense of certainty and clarity –in contrast with all else that I had experienced that day– that I had to always tell my daughters the truth, but that I only had to go as far as they needed to hear and no further. Hannah and Maha would not become the receptacles for my anguish. On the contrary, I had to find the courage to deposit in them confidence, security, and affection, and not my fear. These first decisions, focused on my daughters, were a great source of strength.

I armed myself with the only guide I had at my disposal that afternoon: my experience with my father’s cancer. That experience –lessons from myself at age 17– served me well.

I decided that the first thing I should do was to simply listen to Hannah. I recall that she said little, but that what she did say was expressed emphatically and provided me with essential information. Hannah taught me how important it is to listen to children in order to know what they can tolerate and what they need to hear. Fortunately, children, if you listen to them, tend to let you know exactly how much information they can process. When they get to the point of overflow, they usually stop paying attention. This, I have to acknowledge, is a great coping strategy.

Hannah responded with some frustration to my repeated questioning. “I told you, Mom, I already know everything. You had an examination that didn’t turn out very well, and maybe they have to do more things to you, and that I have to give you a hug.” I replied by receiving and returning her embrace, accompanied by the only concrete information that I had at that moment: “We still don’t know anything... Dilys is taking care of me. She is a great doctor. And, yes...yes, we will go to Disneyland next week... Now, the three of us are going to have some lunch – you, your sister, and I, together.”