Bridges

CONNECTING CANCER SURVIVORS

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Alice (left) and His Excellency, Mr. BAN KI-moon, Secretary-General of the United Nations (right)

Protocol and Protocol

By Alice Hecht

Born in Belgium in 1949, Alice has been working for the United Nations both in New York and in various other countries since 1974. She is currently the Chief of Protocol of the United Nations. She is married and has one son and one grandson.

If you are reading this article today, most likely in the waiting room of Sloan-Kettering, it means that either you or someone close to you is on a protocol (standard treatment regimen) designed to help cure or control your specific type of cancer.

I happen to live under two types of protocols. Since May 2006, I have been on a medical protocol, taking a weekly regimen of Hercepetin and Taxol for breast cancer with metastases in the bones, stage IV. I have been, over the same period, the Chief of Protocol of the United Nations, where I am responsible for ensuring observance of etiquette and a set of rules that prescribes good manners in diplomatic life. As Chief of Protocol, I organize the visits of heads of states, prime ministers, His Holiness the Pope, and other VIPs, as well as the official life of the Secretary-General.

A medical protocol is a treatment (either research or standard care) plan devised for a specific medical condition. Diplomatic protocol is about respecting rules and procedures recognized by all parties involved as those to be followed for good order. The approach and objective of both protocols are similar in their attempt to provide clear and detailed guidance when dealing with a specific situation. But while a medical protocol is ultimately about avoiding death, diplomatic protocol is all about the gentility of life.

My first bout with breast cancer came in August 2000. Found on a regular mammogram, the tumor was only six millimeters. The radiologist had recommended that I come back the next day for a needle biopsy but suggested that I make an appointment immediately with a breast surgeon. My life suddenly broke in two distinct parts: the life "before" and the life "after."

That August morning was one of those hot, steaming New York summer days. When I walked out from the darkness of the doctor's office into the blinding brightness of the day, I remember that the sidewalks were glimmering like diamonds under the sun, crowded with people running about their lives, with their headsets, their shopping bags, their briefcases — walking about as if everything was normal while I had just been branded with the word "cancer." How could they not know what was happening to me? How could they enjoy life while I, who swam every day, never smoked, had a glass of wine only once a week, put money in my savings account, had no debt, had been pushed by an unknown evil from the threshold of health to the brink of death? How could they not see the terror on my face and the word cancer burning on my forehead? How could they just go by and ignore me? I was the center of the universe, and no one noticed me. In my dizziness, I wanted desperately to keep living as if the word cancer had never been uttered to me. Cancer was a word that I had always avoided, as if just to say it gave it power. My life was thrown in the middle of a world shadowed by a horrible disease. The world of the living and the world of death were colliding. Cancer made time stop. The future had been taken away from me.

Two weeks later: a lumpectomy and a diagnosis of clean lymph nodes, nothing in the margins. The follow-up protocol was simple: I would need six weeks of radiation, daily tamoxifen, and six monthly visits to the oncologist. I breathed again. No chemotherapy. No falling hair. No nausea. No tiredness. I could live with that protocol and get the constant humming "cancer" maybe not to disappear but to quiet down. The rest of the world could come back to life with me in the middle. I silently thanked the medical profession for devising a protocol that would pull me out of this nightmare.

At the time, I was working as the Chief Administrative Officer of the United Nations for the destruction of weapons of mass destruction in Iraq. What a relief that after the six weeks of radiation, I could pick up my bags, travel again, go up and down the deserts of Iraq with my colleagues, the weapon inspectors. The cancer had just been a blip on the screen of my health and the illusion of infinite well-being had returned.

Three years later, in March 2003, the launch of the Iraq War had put the United Nations' program of monitoring Iraq's weapons of mass destruction out of business. I was asked to move to Kosovo and manage the logistical, financial, and administrative support of the 6,000 personnel involved in the peace-keeping operation that had emerged during the breakup of the former Yugoslavia.

I talked it through with my husband, and we both agreed that the offer of leading such an important operation was a once-in-a-lifetime chance. In July 2003, I flew to the little Balkan town of Pristina, in Kosovo. The six-monthly visit to my oncologist became just another routine like going to the dentist to get my teeth cleaned. Actually, like a good schoolgirl, I went beyond what the six-month follow up required, and I had a check up every three months when I traveled to New York, alternating visits between the oncologist and the breast surgeon.

I couldn't have led a healthier life than the one I led in Kosovo. I went to bed early, woke up early, went to the gym, worked, ate, and took long walks with friends and colleagues on the weekends in the mountains of Kosovo. Sometime in the winter of 2004, my back started to hurt on and off. I was convinced that I had a pinched nerve and blamed it on lifting weights at the gym. I never mentioned the pain to the doctors I saw back in New York. Wasn't everyone suffering from back pain? Wasn't this just a respectable sign of graceful aging? Take a couple of aspirin and it goes away. But by the spring of 2005, the pain was radiating from my neck all the way to my left hand. In addition to the lingering pain, I started to feel so tired that I had to rest after lunch in my office. On one of my hikes in the Kosovo mountains through hills and fields covered with wild flowers, I told my walking companions that I couldn't walk further.

"I have a pinched nerve in my back," I trumpeted. And everyone nodded in sympathy. Unbelievably, in my mind I was striding in health: the pinched nerve was just another blip.

During the June 2005 visit to my New York oncologist, I still did not mention the pain, and he joyfully told me that I was on my way toward passing the five-year threshold; everything indicated that the cancer had not returned and I should consider myself "cured."

Cured . . . the magic word that every cancer patient dreams to hear one day. The word that gives us hope again for the illusion of everlasting health. Just a couple of months more and by August, five years after the original diagnosis, I could scream to the world that the beast had left my body.

In August 2005, after two years in Kosovo, the United Nations offered me a position in its Geneva office, which I accepted. I decided that before moving to Geneva, I should take care of that pinched nerve and get my full capital of health back in the bank. From Kosovo, I made an appointment with a sports injury specialist. The plan was that I would fly to New York for one week, discuss my new posting in Geneva, fly back to Kosovo to transfer the position to my successor, and move to Geneva soon after. I arrived in New York, saw the sports injury doctor on a Thursday, and was planning to fly back to Kosovo on the following Saturday.

On Friday night at 10:00 PM I got the call from the specialist. He was so sorry to ring me up so late, and even sorrier to have to tell me that the pain in my back was not a pinched nerve at all. My six-millimeter breast cancer tumor had exploded in my bones.

Suddenly, the air was sucked out of the room. The ceiling was crushing me, the walls were closing down on me, and there was no way out. This is what trapped people in a fire must feel — breathless because they're surrounded by thick, black, choking smoke. The smoke here being the words *the cancer has spread*.

The feeling of fear and despair was much worse than the first time I had been given the cancer diagnosis. Somehow, these five years of normal life and peaceful doctor visits had lulled me to believe that the cancer had abandoned me, while, in reality, I had been harboring terrorist cells in my body. They had gone underground for a few years, hiding during all checkups, only to regain strength and attack my body with renewed viciousness. The enemy was reclaiming its lost territory and put roots in my bones. Funny — I never related to my bones. I connected to the soft parts of my body — my breasts, my skin, my lungs, my brains — but the bones? Bones are what linger after death.

On Monday, I saw my oncologist who confirmed that the cancer had metastasized and jumped from stage I to stage IV. The oncologist prescribed three weeks of radiation of my neck and upper back while exploring possible treatments that could keep the enemy at bay. It was made clear to me that I would never be cured. I would have to live with the cancer for the rest of my life. The challenge was to find a protocol to prevent the cells from growing out of control. If found, no one knew how long the regimen would continue to work. I was drowning in the unknown. Was the radiation going to kill the pain that was ravaging my body? How long did I have to live? I no longer wanted to move to Geneva. Just the thought of changing my medical system was overwhelming. Nothing mattered besides the cancer.

The oncologist put me on a hormone blockage protocol, and I went on a one-month medical leave while trying to figure out what to do. But I knew that I had to go back to work as soon as possible. More than ever, I needed the predictability, the serenity, the familiarity of a work structure. Sitting at home doing nothing but going to radiation treatment and seeing doctors who never gave clear answers — only just opened more questions — was the worst.

In November 2005, the United Nations told me that the Chief of Protocol of the United Nations in New York was interested in taking the position I had been selected for in Geneva. I could switch jobs with her! The choice became either go to Geneva or stay in New York and take over the Office of Protocol of the United Nations. The choice amazed me: I knew less about diplomatic protocol than about medical protocol, but I accepted the offer without hesitation. Now, here was a type of protocol that seemed marvelous, the total opposite of what a medical protocol evoked — I imagined receptions, state diners with golden plates, receiving kings and queens, golden carriages, pomp and order.

I started on January 13, 2006, and oversaw my first official function two days later, which was also the occasion of my first "faux pas," as I confused the Ambassador of Japan with the Ambassador of the People's Republic of China.

Unfortunately, as I was stumbling in my professional protocol, I was also stumbling in my medical protocol. The hormone therapy was not working. The little white dots on the bone scans were growing, and in May 2006, the protocol was changed to a weekly treatment of Hercepetin and Taxol. This treatment carries a range of side effects, which tend to move from one part of my body to the next, like the devil jumping out of the box and running around while you try to catch him and put him back in his box. Colds tend to linger forever. I had to give up needlepoint because the tips of my fingers got numb. I buy shoes one size bigger than I did three years ago.

Of course, I started to loose my hair three weeks after the first Taxol treatment. By then, I had been Chief of Protocol for six months and had already received numerous presidents and prime ministers. I'd also organized official functions without a hitch. No one around me noticed that I was wearing a wig. I just got lots of compliments on my new haircut.

But with this cancer treatment protocol, the pain disappeared. Something wonderful was happening, finally: I realized I had renewed high hopes for both kinds of protocol in my life. My life was back on track.

Setbacks came and went. One time, I was traveling with the Secretary-General to Addis Ababa, in Ethiopia, for a meeting of the African heads of state. In the flight from New York, I could see an infection growing in my thumb, under the nail. As soon as I arrived in Addis Ababa, I saw a doctor recommended by the local United Nations office. He told me that the thumb needed to be opened and cleaned immediately. It was 4:00 PM when he drove me himself to a private surgery clinic. When the surgeon started to do the local anesthesia before cutting the nail, I finally started to cry hysterically — not out of pain but out of self-pity. Why was this happening to me? The kind nurses were wiping my forefront and caressing my arms to make me feel better. The whole procedure probably didn't last more than five minutes, and I was still sobbing as the surgeon was closing the wound. But half an hour later, in the car driving back to the hotel, I started to laugh. I couldn't help thinking that the whole problem had been taken care of in less than one hour in Addis Ababa. In New York, I would have spent at least a day in Urgent Care. That cheered me up. I went on organizing meetings between the Secretary-General and heads of states as if nothing had happened. There was no time for me to think about my thumb, which was bandaged as if I had burned half of my arm, creating lots of questions.

"What happened to you?" everyone was asking.

"I cut my finger trying to slice potatoes the day before leaving New York," I answered.

My protocol job has been a life savior. I always say, "What is the worst than can happen in my job? That a flag will be upside down? That a head of state will arrive early or late? That a guest will not be happy because he is not seated next to the Secretary-General?" These problems feel so sweet compared to the unknown of medical protocols.

I have accepted that to be healthy means to live with the health that my body gives me. I swim three times a week, walk an hour a day, lift weights regularly, and go out for diner. And I travel quite a bit. I have a tacit agreement with my oncologist that I can miss two treatments once in a while. I don't ask permission. I just tell her. This allows me to be away for two-and-a-half weeks. When I went for one month on holiday to Turkey, I organized with the help of my oncologist to have the weekly treatment in Istanbul. It took some research and some planning but I was determined to go away for a full month.

I am at the office five days a week, an average of seven hours a day. And I am only at the hospital two hours a week and a few hours more every five weeks and just a couple more hours every three months. I work because, in addition to the wonderful aspects of protocol, work gives me a sense of predictability, security that helps to keep the disease in perspective. Work helps me to live with the cancer and not in the cancer. I'll take the longer hours of protocol at the office any day!

A few months ago, I had to attend an unexpected meeting with the Holy See to plan the visit of the Pope to the United Nations. The meeting was scheduled at 4:30 PM while my doctor's appointment was at 2:00 PM. Under normal circumstances, it should have worked, but I have a doctor who is brilliant but notoriously late. When I arrived at her office, I begged the nurse to get me to see the doctor in a timely fashion. She promised to try her best. At 3:00 PM, she called me to the examination room. I waited and waited and no one came. Eventually, at 3:45, I got dressed, told the nurse I would be back around 5:15, got into a cab, went to the United Nations, attended my meeting, hopped back into a cab, and was back in the examination room by 5:15. The doctor never noticed my disappearing act.

When I leave the office every Tuesday at 4:00 PM and go for the treatment, I say to my staff, "I am going for my beauty treatment." They all know what it means because I've taken them into my confidence and revealed my disease. I am sure that it is not easy for them to have a boss who has a chronic cancer condition. Neither is it for my family. To help with the long wait at the doctor's office and to spend time during the weekly treatments, I bought a DVD player. My current passion is for British TV comedies. I slide into the lounge chair for my treatment, and put on a DVD and headphones. The nurse brings me water and a couple of bags of pretzels, and I pretend that I am at the movies.

But nothing else matters when, as Chief of Protocol, together with the Secretary-General, I greet the Pope as he enters the United Nations and lead him to the lectern of the General Assembly or when I receive the President on his arrival at the United Nations, or when I escort President Sarkozy to the podium of the General Assembly. The disease no longer exists. The only thing that matters is that I am the Chief of Protocol of the United Nations. Diplomatic protocol and medical protocol form a knot in my life. Having one helps me to the other with an ease that surprises everyone. "How can you have such a stressful job while undergoing a weekly chemotherapy cancer treatment?" is the question mostly asked of me. The reality is that the protocol job is what sustains me to face the medical protocol. In cancer, protocol is all about an attempt to rein in what cannot be controlled. In my job, protocol is all about predictability and control, and if I plan well I can predict and control almost anything. And when I face a situation that was not anticipated, I have learned that with a few nice words and a smile there is always a way out.

I don't fool myself into believing that such an easy exit is possible from cancer. I have accepted that the cancer is just asleep, and no one knows if and when it will roar again. In the meanwhile, I am following a journey between health and sickness. My hope is that my medical protocol will allow me to keep on walking in health, at the edge of the abyss of sickness.

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