

doi: 10.3325/cmj.2010.51.173

Words Heal Too

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Think positively! I recently wrote that magical sentence to you. It is a real mystery. How many times have you uttered that sentence to yourself, but also to your friends when they complain about something, but you weren't seriously aware of what it really means? Well, "Think positively" mostly makes me angry, stubborn, or bitter. After the usual turning over of my papers, which they sometimes read in the surgery, leaving out every second line, or with an expression of extreme boredom on their faces, physicians would see me off with that line: "Think positively!"... They say you can learn to do it. Psychiatrists and scientists who deal with neuroscience describe the important effect of your psychological stability and optimism on the treatment and outcome of illness and I have never doubted their claims, but I just don't know how it is done. HOW does one "THINK POSITIVELY" every day, over all those years, with all those relapses, when you have been undergoing treatment for so many years that you have given up counting? Simply because of that sentence, that stupid, simplistic, brilliant curative, but to me personally and to many others, an incomprehensible sentence, in all its simplicity, I decided that our association "All for Her," alongside all its other programs and goals, should take as its fundamental activity the foundation and launch of a Center for Psychological Support for women suffering from cancer. Classical western medicine deals exclusively with our diseases and our symptoms. Why is the holistic approach completely ignored, when the body and spirit are an indivisible unit? That is the reason for the charity campaign our Association launched recently, so that, finally after a year and a half of work, we could finish setting up the Centre given to us by the Croatian Government, under the motto "Words Heal Too."

OCTOBER 2002

I completed the full therapy included in the protocol before the summer. In June, I had already abandoned the clinical study through which I was supposed to be given adjuvant therapy with a "clever" drug.

"You are now completely healthy. Come for check ups every three months."

Yes, yes, I thought to myself. You are healthy only if you haven't been reading the scientific articles for months, which tell you that cancer is a systemic disease that develops on a molecular basis, so the course and outcome of the disease depends on the biology of the tumor, and your immunity. Why do doctors sometimes say things they don't even believe themselves? What healthy person needs to go for a check up every three months?

But still, I desperately wanted to believe that: "You are now completely healthy." One evening I invited my daughter and husband out to dinner at our favorite restaurant, "Starina," to celebrate the end of my therapy. In that pleasant atmosphere, in the middle of dinner, while we were celebrating my return to health, the doctor who had been running the clinical trial I had refused to be part of turned up in the restaurant. He lives in another city and came into the restaurant with some people I didn't know. At that moment, I gave great importance to this seemingly unimportant event (no, don't say I am superstitious). I don't know what a positive perception of an "uninvited guest" would look like, but for me it was as though an evil spirit from a fairy tale had just walked into the restaurant. I spilled the wine all over the table, half my venison goulash ended up in my lap in an instant, and all I could say to my husband was, "Listen, I am not done with therapy... immunotherapy is still waiting for me at some point...!!" The evening was ruined, and I realized that the time to come would not primarily be a struggle with cancer, but a struggle with my own thoughts.

And there are very few people who deal seriously with our thoughts. When on one occasion after my third relapse I asked a prominent Zagreb oncologist who I could go to for psychotherapy, whether anyone in Croatia dealt seriously with cancer patients, he replied, "Actually no, everyone avoids cancer patients." I thought for a long

time why that was so, and I realized that there is no anti-depressive drug or any other psycho-pharmaceutical that could be prescribed, that could wipe out the awareness that you are suffering from cancer. This is why "Think Positively" was something I had to do, constantly and stubbornly. I found a private psychologist and paid for my time with her, wrote my assignments, as though I were in grade school. It seemed easy, but it wasn't. At dawn, while listening to the sound of the street cleaners' vehicles in the distance, the creaking of trams turning around at the last stop at Borongaj, the rattle of trains on the tracks, more audible depending on the wind... for months I struggled with my thoughts like David with Goliath...

I don't measure the time in hours any more, but in the years my daughter has been growing up. The first year after my therapy passed with me writing my doctor's dissertation, which I had abandoned for months, thinking that it would be a waste of time since I didn't know if I would survive. And then I realized that I was still very much alive and I could lose my job if I did not get my PhD on time. I defended my dissertation on May 15, 2003. One more year of three-monthly check-ups passed. Two weeks before each check up, the tension mounted and then, when everything went well, I tried again to be an optimist from day to day and "think positively." It took me two whole years to be successfully rehabilitated in my roles as mother, wife, university teacher, to start to ignore the scientific insights into the aggressive nature of Her2 tumors, and everything I had read about its capriciousness as a prognostic factor. I finally began to feel healthy.

JUNE 30, 2004

Just another routine check up. When the marker results, lung x-ray, ultrasound of the abdomen were done with, I felt very relaxed. Just the breast ultrasound to go. I was on my own territory, but my doctor Boris was not there. He was at a meeting abroad. I was about to leave when I saw a lady doctor who knew me.

"I was just going off duty, but... just wait a minute while I get my coat, I will have a look at you."

"No, there's no need, I will wait for when the professor gets back... I don't want to keep you from going home."

"No problem, just wait!" Those words rang alarm bells. Why this "urgency" for me to have my examination today? Come on: "think positively." I try to calm myself.

Gel, probe, right breast, drops of sweat running down my armpit, from the corner of my eye I watch the gray images on the screen as the doctor analyses them carefully... gel, probe, left breast, she looks, it seems like an eternity... drops of sweat running down my back...

"Listen, there is some kind of cyst on the incision, very clearly defined, it must be a cyst, don't worry. But to be sure, come back on Monday so the professor can have a look and he might decide to aspirate the cyst." When I heard the word "aspirate," my heart stopped. While with one hand I was doing up my blouse, which was stuck to the half wiped gel, with the other I impatiently dialed the mobile phone number of my dear doctor Rada, a family friend of my parents. She has known me since I was a child. Very worried, I went to see her at the hematological oncology department. We went down to surgery together, and an unknown surgeon took one look at the scar and suggested aspiration. "Think positively!" thundered in my head as I walked down the long hospital corridors to the cytology laboratory. Rada, as an experienced cytologist, along with the head of the laboratory, decided to do the cyst aspiration themselves, without the ultrasound, although it was underneath my silicon implant, so there was a risk they would puncture it. I even managed to smile. They looked like two modern day village witch doctors, but with experience and skill, sure in what they were doing. I had complete confidence in them. Now all they had to do was stain the slides and wait. One hour seemed to last forever. "Think positively!"

"You know, this is no place for epithelial cells. I'm afraid this is a carcinoma!"

I couldn't believe it. I called my parents. What now? Rada was livid.

"I said you didn't need that stupid silicon. Let me take it out...!"

I didn't feel anything, I was back at square one, I had no idea what to do next. It was vacation time. My surgeon was away sailing... I didn't know who would operate. The head of surgery in the Zagreb Jordanovac hospital told me honestly and openly that he had no experience with implants, that he didn't know what to do and he could not take on that operation. It was the same thing at the Cancer Institute. I tried to arrange an operation at a private clinic. I was met there with a new monstrous statement uttered by a small, bald, plastic surgeon with a black beard, who was working there in the afternoon:

"No, I don't want to do a radical mastectomy, I will only operate under the condition that I can do a reconstruction of your breast with your own tissue. Don't be angry, but I am an esthetic surgeon and I want my ladies to come out of surgery with a breast..."

I could barely hold myself back and instead of "You moron, I need my head, not my breast," I managed to say mockingly, "My dear doctor, I thought this was a surgery, not a tailor's shop."

I called a surgeon at a German center for breast reconstruction. He was about to go on holiday in three days. I was afraid of another pneumothorax while they were removing the implant.

"No, that won't happen this time while you are having the implant removed," the German doctor tried to convince me during our long telephone call, "Just ask the surgeon who will do the operation to go as far as he can from the tumor, at least 3 cm."

On Monday I met my doctor, Prof. Boris Brkljačić. Before I could say anything, he gave me a fatherly hug: we had already become quite good friends.

"I know all about it. I had a look at your findings... it really doesn't look like a carcinoma on the pictures, those carcinomas aren't like they are in the books any more," he added.

The surgeon with whom I finally arranged to remove the implant laughed kindly as I passed on the suggestion of his German colleague.

"Well, you know, Dr Žic, I don't think you don't know what you're doing – I am just a bit of a control freak."

On the evening before the operation, Dr Žic was on duty and he called me into his surgery: "Come on, after the recommendation of this German colleague, let's draw that circle 3 cm from the tumor, where I'm going to operate tomorrow, if it bothers you so much." And he drew a circle around my "lodger." I realized that that symbolic tattoo was only intended to gain my full confidence in the sleepless night before the operation. He didn't need that black circle, I did, and I still remember this as one of the brightest examples of a "bedside manner" from a man who not only loved his work, but who also knew the importance of doctor-patient communication at all levels.

I was entertained by comforting a young girl in the bed next to mine, a student at the arts' faculty, 21-year-old Ana, who was also going to have surgery the next day for breast cancer.

JULY 12, 2004

My silicone implant was removed; finally a radical mastectomy was performed, and they also removed a part of the pectoral muscle. Pathohistology: tumor 0.8 cm, grade III, and the receptors the same as in the primary tumor – estrogen receptor 0, progesterone receptor 0, and of course "my friend" Her2/+++ . I remembered my "evil spirit" of two years before in that restaurant. Couple of days before I left the hospital, I planned what to do next, and I already knew it all. I went round three hospitals in Zagreb. All three prominent Zagreb oncologists were united in their opinion that after a surgery for a local recidive no additional therapy was necessary. At the Cancer Institute, the lady doctor was actually very picturesque in her thoughts, "You know a local recidive is dealt with by surgery, perhaps you could have a bit more radiation for it, if there is 'room', since you have already undergone radiation in that area, but I wouldn't give you any form of systemic treatment, because in any case, whether you have micrometastases circulating around in your body only God knows!" Although partially happy, because I had three uniform opinions that the surgery had been sufficient, still... I was not totally at rest. I was troubled by what I knew about Her2 positive tumors, and by the negative hormone receptors. Hadn't that God the doctor had mentioned said, "Help yourself and I will help you." I went back for another consultation with my doctor at the Rebro University Hospital Center. I liked her best.

"Are you sure I don't need any kind of therapy?"

"Yes I am. I would just like to follow you from now on." (Later my friend commented jokingly: Where does she want to follow you – to the toilet?)

"You know I am thinking about going to Paris for a second opinion??"

"Yes, that is your right, go ahead."

"I would love for you to be right and that I don't need any more systemic treatment, but what if I come back from Paris with a different opinion, will you respect it?"

"Yes, of course!"

I spent those days in an intense "investigation" of all the authorities of Croatian oncology, of whom not a single doctor wanted to write down and sign his opinion on unnecessary therapy. Finally I understood one thing "*Medice cura te ipsum*." Which in this case meant: "Vesna, take things into your own hands, take responsibility for yourself." I made my decision. I was going to Paris. But no, not tomorrow... before that I was going to the seaside for two weeks, it was summer, everyone was at the seaside. I was going to go to my Vranjica. I slept, swam, rested, I was in a great mood...

And around the time of our Mediterranean siesta, all was quiet in Vranjica, only the tireless cricket in my cypress tree rattled its heavy iamb, reminding me of my childhood, elementary school, and the lines learned long ago by the Croatian poet Nazor, which we all had to learn off by heart... So, drowsy in the noon day sun, I looked out to sea at the distant horizon, there somewhere where the sky and the sea meet... and my thoughts rattled their own "heavy iamb." How much more time would I need to learn once again to THINK POSITIVELY? Although in the rest of the world psychologists and psychiatrists have long been part of the oncological team, and psycho-oncology a sub-specialization of psychiatry, the Croatian health system has still not developed or implemented systematic psychological support for oncology patients, nor for any other seriously or chronically ill patients.

AUGUST 19, 2004, CONSULTATION IN THE PAUL BROUSSE CLINIC, VILLEJUIF , FRANCE

Dear Colleague,

Today I received for consultation Mrs. Vesna Andrijević-Matovac, who underwent a mastectomy for a bi-focal breast tumour three years ago, and therapy by 6 FEC 75. The patient underwent repeat surgery for a nodular recidive. In view of the relatively quick recidive of the residual node, there is a suspicion of spread to the surrounding pectoral muscle but is not possible to perform new treatment by radiation. I therefore propose as preventive therapy, six new rounds in combination of Taxol-Herceptin. For this young woman, in fact, who has negative hormone receptors and highly expressed Her2, this combination has the greatest likelihood of offering her additional protection from the risk of her tumour developing once again.

Thank you for the support you will provide for her.

With best wishes,

Professor Claude Jasmin

The bill for this consultation was **25 Euros**.

My sister, an ophthalmologist, and I spent that entire afternoon on the blue and red line around Paris, but I don't remember seeing anything or that we got off at any of the stops. I only noticed that we had returned to the Eiffel Tower, and then Notre Dame, that the sights went by, but we did not get off, for a few hours. That was our time in which all hope was gone that I wouldn't have to undergo chemotherapy again... talking and thinking in the summer heat, while we comforted each other in turn, and the only thing that cooled our hot cheeks were our salty tears. Finally we were drawn by the smells from a nearby café, and got off the bus at Notre Dame. Hot French croissant and superb coffee helped my "think positively" to resurface, just as Prof. Silvija Altaras-Penda, my "psycho-support guru," always told me: "It's not important what happens to us, but how we deal with it."

APRIL 2010

At the Center for Psychological Support for women suffering from cancer, run by the Association "All for Her" which we are planning to open by the end of May this year, alongside the support of professionals, psychologists and psychiatrists, we want to offer sick women and their families all forms of psychological support during their treatment and rehabilitation, through group therapy and workshops, but also individual consultations. We are now in the process of signing a Cooperation Agreement between our Association and the Clinic of Psychology at the Rebro University Hospital Center. We believe that the profession will be glad to cooperate, realizing that "THINK POSITIVELY" is not just a phrase nor just a linguistic structure, which is easy to say, but a process, in which it is necessary to work with oncology patients, over a long time, systematically and seriously. During our treatment, psychological support is not only necessary, but it is absolutely vital. Because, if you didn't already know, alongside all the other forms of therapy used,

Words heal too!