

Rita's Journal Entries 2001-2009

Introductory comment from Estelle Disch

Contextual Notes by me are preceded by ED and are in brackets.

Although almost all the entries included here relate to Rita's health, I have included an occasional entry about things that excited her or exhausted her, in order to provide a sense of her life beyond dealing with cancer.

Names of medical professionals are pseudonyms

Steven is Rita's oncologist

Marcie is Rita's primary care physician

Dr. B is the radiologist who radiated her lung

Other doctors who Rita saw briefly are identified by initials (e.g. Dr. X, Dr. T)

Family names are as follows:

Federico (Fede, or Fed) is Rita's son

Naima is our daughter-in-law (Federico's ex-wife and mother of Layla)

Layla is our one grandchild

Edith is Rita's older sister, living in Argentina

Jaime is Edith's late husband, also from Argentina

Alicia is Rita's younger sister, living in Argentina

Other relatives or friends are identified as they appear.

There are two standard tests mentioned often in this account. The CA 27/29 test measures the level of CA 27.29 antigen, which is found in the blood of breast cancer patients. The CEA (carcinoembryonic antigen) is a marker for the presence of colon, lung, and liver cancers. This marker may be used to determine if the breast cancer has traveled to other areas of the body. In Rita's case, the 27/29 was the best indicator of cancer activity.

Journal Entries

Journal of my third metastasis (I hope so, that it is not lung cancer)

[ED: Rita was hearing odd sounds in her lung. Finally I heard it twice, like a quiet click.]

April 8, 2001

On Tuesday April 3rd I saw Dr. T, a pulmonologist. At first I didn't like him because he would not look me in the eye. After a while he got more interested when he heard my

cancer history. After examining me, he agreed that a bronchoscopy was in order. I had the bronchoscopy on April 6th and he saw “something” in a bronchial tree near the part of my lung that has collapsed. [ED: a small area at the bottom of Rita’s left lung was collapsed due to fluid buildup in the pleura, the sac surrounding the lung. The broncoscopy was related to what might be going on within the lung itself, not the pleura.] He took material for a biopsy, swipe, etc. There are three options: metastasis; lung cancer; not malignant. I am looking at my old journal and notebooks from 1983-1984 to understand when I went on Tamoxifen and when I started the Hippocrates diet.

Started drinking wheatgrass juice again...I pulled out the Hippocrates books.

Last night we went to a friend’s house for Passover with Naima and Layla. I felt sad.

Today I feel a bit better. Getting ready for the fight.

April 9, 2001

Last night I spoke with Edith. Jaime starts chemotherapy today, at home, he sounded quite good, can walk, still taking pain killers, methadone?

Last night I slept quite well. The wheat grass? I am drinking a glass right now. I am going to look at the eighties history with Tamoxifen and Hippocrates.

April 10, 2001

I called Dr. T to see if he was going to be there on Friday and his secretary called him and he called me back. “The rumor is that it is from the breast. The tumor markers test is not back yet, but that is the rumor.” I practiced breathing and being “gentle” while waiting for him. I was relieved, not lung cancer. I feel I can beat it again. I will call him on Friday. I think this is not the worst, though of course a “mucous plug,” like a friend had, would have been wonderful news. But it was not meant to be. I’ll deal with it.

April 14, 2001

Yesterday Dr. T confirmed over the phone that the cells were “compatible with breast.” So, no lung cancer at least. Started looking on the web for wheatgrass stuff.

This is what I can put together, looking at old diaries:

In August 1982, I had some coughing fits. In November, balance problems.

In 1983, June 27, hard to swallow. June 28, LaPaz.

August 18, 1983, started Tamoxifen. Took it for 4.5 months. The last week, only one pill (reduced dose)

December 1983 Started Hippocrates

January 1, 1984 Stopped Tamoxifen. Did colonics, enemas, juices, fasts

March 8, 1984 Steven wanted me to do Tamoxifen and diet together

June 28, 1984 started Tamoxifen because I was going to Argentina July 19

September 27, 1984, Steven, “I am well.”

June 1991, CAT Scan. I was going to have a broncoscopy but it was cancelled. Dr. T took a look and saw no difference from 10 years ago.

I am not scared and I feel I am going to beat this round too.

April 19, 2001

The noises in the throat are gone. The cough is less. Tomorrow I see Steven.

April 20, 2001

Just saw Steven. Three options: radiation; photolaser; Arimidex.

Arimidex, and then a CAT scan in 3 months, now we know what to look for. The “feeling” better (less noise) may be because the biopsy opened a space, so I can breathe better. Too bad I did not record when the wheezing was less. So now, Arimidex! Make it work! [ED: Arimidex is a hormonal intervention that works differently than Tamoxifen.]

April 22, 2001

I started Arimidex 2 days ago. Last night I felt warm in the body. Is this a prelude to hot flashes?

April 26, 2001

Yesterday I started working out at the gym. Today I did another routine. My legs hurt. I am sad. One day at a time, but it is hard. I can't call a friend I want to talk with in Argentina while I am in this mood. [Note from Estelle: That friend was very sick with cancer and died 4 months later.]

May 5, 2001

On Friday I noticed some spots on my breast scar. I called Steven to make an appointment to see him before we go to France, so I'm not worrying about local recurrences.

May 16

Yesterday Steven looked at my scar. He could see where the spots had been. Said that that is how recurrences look. It could be a “flare up.” When patients start taking a new medication, about 10% flare up, have pain in the bones. But they still respond to the treatment so this may have been that. It makes me more aware than before of how close the cancer is to resurfacing and makes me more set on resigning from the Board of Sojourner and also decreasing my workload at Union Institute. Like I really have to take care of myself.

May 22, 2001

The new bed has been here since Wednesday and it is OK. The pain in my side that I sometimes had in the morning seems to be diminished.

I am doing the wheatgrass. It is easy with the electric juicer. I am going to take it every day until we leave June 3rd.

May 22, 2001

I requested a leave of absence from the Board of Sojourner for 6 months, really glad I did that.

Nice news: A woman from Brandeis wrote a very favorable review of my book for a British historical magazine.

June 1, 2001

I have been worried again about noises while breathing. I have noisy breathing in general and yawn a lot. I also have big sneezes once in a while. The scar looks OK, though, I must remember that there is nothing to do but wait for the CAT scan, and it is now about 6 weeks. Started April 20. Another 6 weeks. Let's go to France and see how it all goes. Working on impunity and the paper on the Grandmothers.

We had a good meeting at my house, Betty Furden, Renee Shapiro, and me, about refocusing the Women's Community Cancer Project in order to put our energy into the newsletter. It makes sense, absolutely. [ED: Newsletters and Fact Sheets from the Women's Community Cancer Project will be accessible on this web site.]

I was thinking, if I can last 13 more years, I will be 80! Nothing to complain about, if that is the case.

June 7, 2001

In Paris. I'm doing quite well with my back. My chest is less tight. I do hear a noise when I lay on my left side, not on my right side. I am glad I told Estelle about it. I just heard another noise after yawning. Who knows what is going on with my bronchia? If there was an improvement because of what Dr. T did, or because of the Arimidex, we have to wait and see, which is quite nerve-racking. It is now about 6 weeks of Arimidex.

June 11, 2001

In Aix au Provence

My chest didn't feel so tight today. I did the back exercises and also took 2 ibuprofen. One day at a time.

June 12, 2001

Yesterday I had a tight chest. I think I need to eat small meals, not big ones. And the breathing is more or less the same.

June 15, 2001

I will calm down and send good energy to my body. My chest has been tight and there are some noises in the breathing when I lie down... We shall see.

[ED: We had a very good time in France, starting in Paris where we stayed with Rita's old friend Dick and then in Aix au Provence where Rita's nephew Martin and his wife Francoise showed us around. We saw Martin's daughter Deborah also. We did touristy things every day and Rita kept up with everything in spite of her worry.]

June 18, 2001

Back in Cambridge

Actually the chest has been less tight June 16 & 17 and now. Maybe the ibuprofen, reacting with the other drugs? Who knows??

June 24, 2001

Quite a bit of noise in my chest, especially when I lie down on my left side, where the tumor is. And the wheeze is there, but not as strong as it was in March. I have had hot flashes, very hot.

Went to the gym and did the treadmill for ½ hour.

Good idea from Estelle- to gain time, see the photodynamic therapy doctor to see how much I like him (or not) and learn what the procedure involves.

June 26, 2001

I made an appointment to see Dr. F, the doctor who does photodynamic therapy on July 3rd. I am worried that the tumor may be growing in my lung because of the noise and some cough.

I had the bronchoscopy on April 6th. By April 19th the noises were gone. Started Arimidex on April 20, noises started again around the end of May.

June 27, 2001

I read in the pill book at CVS that Arimidex should be taken alone, away from meals for better absorption... Steven didn't mention that. I take it at 5pm alone. Big hot flashes now, they started June 17 when we came back from France. I feel better today. Went to the gym.

June 28, 2001

Last night there was much less noise when I laid down to sleep. Big hot flashes.

July 2, 2001

It is a roller coaster. The noise is less when I lie down but there is wheezing still and a lot of yawning. What the hell is going on? Tomorrow I see Dr. F finally.

July 3, 2001

I saw Dr. F. The photodynamic therapy is not as simple as it seems. Three broncoscopies and 30 days avoiding sunshine or bright lights and maybe a stent is inserted, a little metal thing to keep the bronchia open. They can do it all in a week, but now I want to know more about radiation—how long, how much, how effective. He said there is external radiation and internal (with a bronchoscope), but you do the external first. It seems a bit too much to have 3 broncoscopies in a week and then rush to my Union Colloquium in D.C. Investigate more. Cool down. I am not going to suffocate. It is just uncomfortable. He also said that no wheezing can also be because the tumor grew and blocked the

bronchi, so it is not always a good thing. So now I am almost happy I have wheezing, it means it did not grow 100%!!!

July 9, 2001

My breathing has been OK for the last 3 days. I had one bad day on the second day of the Colloquium. Less yawning also.

In one week, CAT scan!!!

July 19, 2001

Yesterday I saw Steven with Estelle. CAT scan looks the same—not worse nor better. He said to “sit tight” because the clinical symptoms are better and that a small improvement may not show in the CAT scan. Makes sense. Also that if the wheezing stops because the tumor grew it would get worse/increase before it stopped. Good information. ... All in all, good news.

August 7, 2001

Yesterday Estelle tracked down Marcie [primary care doctor] and that is how I know about the compression fracture. [Note from Estelle: Rita had back pain and was of course concerned about a metastasis in the spine.]

August 21, 2001

Yesterday I had good news from Marcie. After consulting with Steven, they both feel it is not a metastasis. This is the first good news in a long while so I asked for physical therapy.

August 26, 2001

I feel quite good. Almost “no noises.”

September 5, 2001

I am doing physical therapy.

October 3, 2001

Yesterday, saw Steven. CAT scan is “stable,” same thing, no more, no less, but I don’t have any symptoms. So, sit tight, again. Go to Argentina in December and have a CAT scan in January when I get back. It is 5 months now of Arimidex. In the meantime, keep living as well as I can. I am now going to move forward on the back-- see Marcie and get a referral for the Spine Center before I go to Argentina.

November 18, 2001

I feel like there is a lump on my right side, where the mastectomy scar is. Maybe a lymph node. Scary. The wall of the chest felt tight and like itchy. I’ll try to relax and work and will see how it looks tomorrow. And how it feels. Radiation? Otherwise things seem

to be going more or less OK. I went to the Spine Center. Will visit for more tests, unless this is another recurrence, in which case the spine seems less urgent. Oh, God-----

November 19, 2001

I did the right thing this morning – set up an appointment with Steven for next week. Nothing before.

December 14, 2001

Many, many things.

Steven says it doesn't look like a lymph node.

The Spine Center was interesting but I don't really qualify because they get their best results 1-3 months after the injury. Suggest I get another X-ray to see how it develops.

The MRI was a horrific experience. They sent the report to Steven, mentioned something in the liver. He was not worried.

2005

November 5, 2005

On the plane going to Colorado Springs, I got ideas for a collection of essays, "Buenos Aires Collage." I feel excited. I think there is something there.

[ED: One of Rita's notebooks has Argentina notes from early 2006. We spent about 2 months there that year. Family, Grandmothers, Saladillo, La Plata. It was the year that friends from the US visited Buenos Aires. Rita interviewed Grandmothers Estela Carlotto and Rosa Roisinblit, and also interviewed found grandchildren Juan Cabandie and Victoria Donda. I gave a talk there at the University of Buenos Aires. Only once in those 2 months does Rita mention a back ache (Jan 24). We were very busy in Argentina and Rita kept reporting going to the gym along with so many other activities. In short, she was in good shape. We returned February 17.]

The Last Recurrence – 2006

[ED: This entry has no date.]

I had spent 4 great days in Eastport, Maine with Estelle and her Brother Bob and his partner Sylvia and we did a lot of running around. Our Eastport trip had become an annual event before Estelle's departure for a month in Newfoundland. I usually returned to Boston by bus. It was on the bus that I first felt a tightening in my chest. I could not take a really deep breath. I tried several times and it never felt deep enough. It was as if a tight band had suddenly been wrapped around my chest and I could not push against it to stretch it. I changed positions different times—bent forward and backward, stretched my arms, loosened my pants—no difference. I thought, I must be too tired. Too much running around. After all, I was 71 years old and though I had been doing a strong woman class at

my health club for 2 years, I thought I had to accept some limitations. I was also yawning a lot. I decided I would try to sleep and finally dozed off. When I got to the terminal in Boston I was busy getting my things and trying to get home and did not pay much attention to how I was feeling. I thought walking would get my system going normally and that the tightness would surely go away. It didn't. When I got home, climbing 3 flights of stairs to my apartment was a chore. Because I was also yawning a lot I told myself that I was probably too tired from the trip. I went to bed, thinking that a good night's sleep would get me back to normal.

But in the back of my mind I kept asking myself, "Is this another recurrence?" I called my oncologist but he was on vacation. At a loss for what to do, I called Marcie, my primary physician, a woman whom I saw for non-cancer-related problems. At that point, not wanting to believe that this was another recurrence, I was thinking that my symptoms suggested a heart problem.

August 3, 2006

I have an apt. with Marcie at 1:45. Estelle is back. Big help!!

Yesterday I had the CAT scan and in the afternoon Marcie's office administrator called and said that Marcie wanted to see me today. Incredible. How can it be so fast? I am sure they found something. But what?

Writing will help me keep this story straight and give me space to think. I liked doing the prep for the CAT scan at home instead of sitting in the waiting room at the hospital.

Just got a call from the hospital, apt. with Dr. M, on August 7. He is replacing Steven while Steven is on vacation.

Marcie told me there is liver involvement, "adhesions" in the lung, and bone metastasis in my back. I think that is the fractured vertebra. [ED: From a previous fall.] She was great, held my hand and touched my leg. She said that Dr. M is nice and that I will like him. She thinks they will change the medication.

Monday August 7, 2006

After we almost died kayaking in NH on the Pemigewasset river, I am nauseous.

According to my 2001 datebook I started Arimidex on April 21, 2001. I fell in Key West on January 22, 2001. Marcie did an X-ray on March 27th. I saw pulmonologist Dr. T on April 3. Bronchoscopy April 6. On July 18, Steven told me to sit tight for 2 months. Had a bone scan on July 31st. Compression fractures T12, T13, T14? [ED: I think those were related to the fall.]

Notes taken by Estelle at the appointment with oncologist Dr. M.

- 1) There are new spots on bones. Pelvic bone and L5. Get a bone scan for more information.
- 2) Should she stop Arimidex? Wait until Steven returns to decide.
- 3) He'll repeat the liver and tumor marker tests.

- 4) She should walk every hour to prevent blood clots.
- 5) How long does treatment with Arimidex typically last? The cells are smarter the next time around. There are other hormonal treatments but if it has spread too far, chemotherapy is more effective. Hence the need for the bone scan.
- 6) There is an area of thickening at the bottom of the esophagus, which might or might not be a change.
- 7) The liver is the biggest area of concern. There are a few different spots and one significant area of involvement, 7 centimeters. A liver cyst has been there all along.
- 8) Consider an inhaler to assist breathing, but use it in the daytime since it can interfere with sleep.
- 9) There is a small hiatal hernia which has probably been there all along. Those are very common.

Rita's last appointment with Steven was in June 2005. Her last CAT scan was with Marcie in 2004.

August 8, 2006

I am starting a file on fighting my 4th metastasis.

Enrolled in Breastcancer.org

Screen name: R72hope@aol.com

Friday August 18, 2006

Summary of ED's notes re. appointment with Steven:

- (1) re. Lung. Go to Beth Israel for light therapy to deal with a 1.1cm endobronchial lesion. The left lower lobe is more collapsed than it was previously. There are also tiny pulmonary nodules which Rita shouldn't notice.
- (2) Re. Liver. The largest lesion is 7.7cm x 5.8cm. Liver test slightly elevated. If the large spot shrinks to 4cm, they can eliminate it via Radio Frequency Ablation. Or they can surgically remove it.
- (3) Re. Bones: There are scattered dense areas that are sclerotic, meaning that there is more calcium in those areas due to irritation of the bone by the cancer. The bone responds to cancer by adding calcium. They have probably been there a year or so because of the calcium buildup., and have probably progressed in the last 6 months. There should be no pain in those areas because the bones had the opportunity to repair.
- (4) Re. Treatment: Stop the Arimidex. New aromatase inhibitors sometimes work but Steven recommends chemotherapy first. If that works well, can switch back to hormonal intervention. He had one patent on hormonal manipulations for 29 years. Xeloda is the chemo he recommends. Two pills per day for 14 days, then 7 days off. Repeat for 3 cycles and then look at tumor markers, which in Rita's case should reflect the effects of the drug. No hair loss, no

nausea or vomiting. Major side effect is hands/foot syndrome in which hands and feet peel and are painful. Manage that with heavy moisturizers, socks and gloves at night. Or take a break from the drug. An occasional person has blood count problems; they'll do blood counts to check that.

August 30, 2006 – Estelle's notes

The Half-Day Procedure

August 2006: Rita has a 1.1cm tumor in her lung. It is blocking the airway (bronchia) to the left lower lobe. She has been having trouble climbing stairs, yawning a lot (sign of not getting enough oxygen) and has a whistling sound when she breathes as the air pushes past the nearly-completely-blocked airway.

Based on CAT scan and chest x-rays, she may be a candidate for photodynamic therapy – a procedure that involves injecting a substance into the body that settles in cancer cells. When a special light is shone on the cells (via bronchoscopy), they die. Then the doctor goes in 2 days later to remove the dead cells. Dr. F at Beth Israel Deaconess is an expert at this and Rita has been referred to him. Step one is an evaluative flexible bronchoscopy. That occurred Tuesday August 30th. They sedated Rita. A Fellow did the procedure with an assistant spraying lidocaine into the tube the whole time. One of Dr. F's colleagues, Dr. O sat at the computer watching, requesting certain photos (which he gave us). They allowed me to stay in the room and watch. At the end he recommended the next step: surgical tumor removal with the possibility of stent placement to keep the airway open or light therapy. He was vague regarding exact treatment. Later we learned that it would be either stent or light therapy since once a stent is inserted they cannot do light therapy. He said that the next procedure, a rigid bronchoscopy, would very likely bring her substantial relief regarding breathing. Rita agreed to proceed and it was scheduled for a week later. They predicted a procedure of an hour and a half starting at 9:30; another hour and a half or two of recovery; and then Rita will be on her way home. We are skeptical that she'll recover from anesthesia quite that quickly but expect her to be home that day even if she is released later than 12:30.

Wednesday Sept 6: Rigid bronchoscopy under general anesthesia. Fed and I take her in, stay with her until they wheel her into surgery. In the process of dealing with consent forms, Dr. N, another fellow in Ernst's team, informs Rita that there is a 1% chance that she will die in surgery from unstoppable bleeding. We are all shocked; 1% seems high and there was no prior discussion of this. A nurse says, calmly, you can change your mind. Right, it's all decided and there Rita is in a gown on a gurney with all the pre-operative procedures done and they are about to give her a sedative. She insists on talking with Dr. F (whom we have not yet met) before being drugged. Finally he comes in, is optimistic, upbeat, and says he'll discuss next steps with her when she wakes up. Fed asks, what might those be? He refuses to say. Rita agrees to go forward. I leave to go to work and worry until I hear that she is out of surgery.

But there have been complications. The tumor had penetrated the wall of the bronchia. Removing it left a hole in the tube, allowing air to escape, which collapsed the left lung. They inserted a stent, 4cm x 1.2cm to cover and seal up the hole. They inserted a chest tube to suck out the air and any fluid that had accumulated in the chest so that the lung could reinflate. At the end of the surgery the lung was airtight, according to Dr. O, whom I met in the parking garage at 6pm when I arrived after my class. What luck that I ran into him so that I could get all the details direct from one of the doctors. It was he who explained that once a stent was inserted, light therapy could no longer be an option. I asked if the stent would stay in for the rest of Rita's life. He said probably.

Wed evening: Follow-up CAT scan. They wanted to check the status of the air in the chest cavity; there had been a bit there at the end of the surgery. A small amount of air will reabsorb on its own. The CAT scan showed that there was no additional air so all was well. Meanwhile, Rita was not allowed to eat or drink because of the CAT scan—not because of the scan per se, but because if they saw something troublesome, they wanted her to be ready for a subsequent anesthesia. The IV drip was sodium chloride, which left her very thirsty.

The IV drip created a need to pee often. To do this, three tubes had to be dealt with: The chest tube, attached to a vacuum pump plugged into an outlet in the wall, had to be disconnected and the pump carried with her. The oxygen tube had to be removed from her nose and left on the bed; and the IV pole had to be taken along, being careful not to pull its plug out of the wall. Every hour or so we went through this. It turned out (we learned the next night) that her bladder was not emptying correctly because of the morphine, so though she peed (with great difficulty; standing, sitting, trying different positions), not much pee was coming out, yet fluids were constantly going in. Fed and I went to find some supper in the cafeteria around 10pm, leaving Rita alone. When we got back an hour or so later, she was desperate to pee; had called for the nurse 3 times and no one came. We got her to the toilet and did not leave her alone again except for a few minutes here and there to go pee ourselves and only right after she had peed. I slept in a chair in the room. Fed slept on a cot in the visitors' room. It is against the rules to spend the night in a double room but I convinced the nurse to let me stay since I could be helpful regarding toileting, even though they did not like the idea of me disconnecting the pump and the oxygen tube (these are no-brainers). Deb, a wonderful aide, got Fed a cot, got me a huge chair that tipped back, and got both of us pillows and blankets and for him even a fitted sheet. She said she'd make sure we were allowed to stay.

Thursday September 7. At the 4am vitals check I asked the nurse what time the doctors made rounds: One would come between 5 and 6; the team (with students in tow) would come between 6 and 7. I woke Fed for the team visit and they talked about a chest x-ray. I left to go home and walk Lucky. My friend Elaine, bless her, had walked Lucky and fed her twice on Wednesday so that I did not have to go home. Thursday morning Fed stayed

with Rita and I took Lucky to Fresh Pond for half an hour (walking both of us). I also went to Rita's to pick up her chemo pills and headed back to the hospital. Fed told me that there was a crisis: Dr. 1% (aka Dr. N) had listened to Rita's lungs after rounds and said he thought the stent was plugged with mucous and that she'd need a flexible bronchoscopy to remove the mucous. Those procedures are hard on Rita. Both times that she has had one she spiked a fever a few hours later and had nasty chills for 2-3 hours, not to mention exhaustion. I was very worried that that attack on her body would be very uncomfortable in the midst of recovering from anesthesia and dealing with morphine for pain relief from the chest tube. Luckily, Dr. 1% was wrong; chest x-rays showed that the lungs were fully open. Dr. F himself came in to tell us that.

In the late morning the nurse practitioner from the thoracic team shut off the vacuum pump. They did an x-ray 2 hours later and Rita was doing fine. So they then clamped the tube, meaning that her body could not drain any more fluid and had to handle what was in there (any leftover air) on its own. 2 hours later, another x-ray showed that her lungs were doing fine, so the chest tube could be removed. I insisted on watching, given that I wanted to be prepared for any home maintenance that might be necessary. The nurse removed a sopping bandage and cut one of the 2 stitches (the other will stay in until Rita sees DR. F for follow-up in 3 weeks). Then she took a piece of Vaseline-embedded gauze and wrapped it around the tube where it entered Rita's chest (between 2 ribs, at breast level). She then yanked it out very fast and stuffed the gauze against the opening to keep air from getting in. Rita yelled and then reported pretty quickly that the pain was better. The tube inside her chest was about a third of an inch in diameter and a foot long. Mama Mia. We were both shocked; no wonder it had hurt so much to have it in there. Dr. O had told me that Rita would feel much less pain once the tube was removed.

Rita was feeling well enough to consider spending the 2nd night alone when we began to confront more seriously her trouble peeing. Of course, she worried that there was an obstruction caused by a recurrence in or near her bladder. It didn't seem wise for her to head home with that difficulty, which was improving a bit but not much, so we started talking about it with the staff. One nurse thought it was caused by a Foley catheter but as far as we knew she had not been catheterized; she did not return from surgery with a catheter. Another thought she might have a UTI, though she was being loaded with antibiotics; one thought maybe the antibiotics had provoked a yeast infection that could have that effect. Finally a nurse we liked a lot (Smart Nurse) offered to do a bladder ultrasound to see how much urine was retained after Rita peed. It turned out to be .6 litres – a lot. She said that failure to empty one's bladder is often caused by pain killers, so immediately Rita decided to stop the morphine and go with just Tylenol. I decided that I should spend the night again and the nurse, though hesitant, did not stop me. Fed had arrived after work around 6:30pm and I went home around 7 to hang out with Lucky, handle e-mail, and empty Rita's mailbox. I went back to the hospital at 10:30 with 2 yoga mats so that I could get better sleep on the floor. They let me in through the security desk

in the main building, a signal that the nurses were going to let me spend the night, since visiting hours were over at 9.

At 11pm we confronted a new dilemma: temp of 100. Smart Nurse asked if Rita had been using the breathing device – to strengthen her lungs—saying that failure to practice deep breathing could cause a temperature rise and possibly pneumonia. Rita had tried it earlier when Smart Nurse discovered the device on her table, still in its packaging. Rita hated it because it was very painful, and said she'd start doing it when she got home. The nurse suggested hugging a pillow against her chest, so that it wouldn't "feel like her lungs were going to explode." The fever provoked us into action. Rita did 30 breaths right away (and holding a pillow did help). I woke her up at 3am to do it again. And at 4am, before the next round of vitals. She passed: Temp normal at 4:15am. Whew. The last thing we needed was another problem that would distress her and/or keep her in the hospital.

At 5:30am one of the thoracic MD's came in and said she'd be going home; last night's x-ray was fine. At 6:30 the team came very briefly and also said she'd be going. Later they did one more x-ray and another round of blood work before clearing her to go. (They did CBC and blood chemistry each morning.)

I left at 6:45 to go to work; Fed visited on his way to work. Susan visited later in the day. I picked Rita up at 2:15 and we were on our way. We took a half hour walk at dusk, she did her breathing practice, we had supper with the kids at 7:30, went to bed around 10:30 and slept 13 hours. Rita coughed violently in the night on and off but got back to sleep after adjusting her position, and I slept through the noise.

Sat Sept 9: Rita's 72nd birthday. Shower. Dressing removed, replaced by bandaid. Lots of phone calls from family and friends. Less yawning. Progress. 40 minute walk at 6pm.

Sept. 15: The forced coughing to remove phlegm from the lungs has been exhausting. Rita sounds like she is dying of consumption and her lungs rumble. The docs say that this is all normal. She is reluctant to go far from home because if she starts to cough people will think she is spreading TB or something. And she has to do the breathing exercises several times a day—not an easy thing to do out in public since it's so distressing to observe, let alone do. Why don't they prepare patients for this? This goes with having a stent put in. They mentioned stent, pre-op, but never mentioned that stent implied a lot of other nasty stuff.

Rita starts cycle 2 of chemo today. Two weeks of pills, then a week off. After cycle 3, we'll see the oncologist (Steven) again. So far her white count has not been negatively affected by the chemo. She'll see a radiologist soon to see what he suggests re. radiating the spot in the lung.

Sept 21, 2006

[ED: Based on info in the health notes notebook, Rita was concerned about her relationship with Steven, found him with “no direct communication,” experienced his secretary as a barrier who said things like, “Dr. Lange has agreed to see you,” which drove Rita nuts. She asked for Marcie’s help. Marcie eventually talked with Steven, who she said was tense. Steven, unfortunately, was dealing with his own cancer crisis and was, I think, off his game.]

September 22, 2006

Steven recommends radiating the lung. And he discussed how tumor markers respond to Xeloda. After 2 cycles, 40% have higher markers; 20% have the same markers; 40% have lower markers. In short, it will take a while to know whether the drug is working.

September 28, 2006

[ED: Meeting with the radiologist, Dr. B to discuss radiating her lung. The stent keeps the airway open but does not address the tumor, which could collapse the stent. Hence the need for radiation. Four-to five weeks, 5 days a week, 10 minute treatments, starting October 10. Side effects: (1) swallowing discomfort in esophagus, starting 2-3 weeks into radiation treatment and going away in 2-4 weeks. (2) Dryness. (3) Heartburn. (4) Fatigue is common towards the end of treatment. And fatigue might be compounded since the Xeloda also causes fatigue. There are appetite boosters if necessary. Lungs can repair themselves as cancer cells are killed. Xeloda probably made the esophagus more sensitive to radiation so take small bites, eat soft foods. He would shorten the treatment if there were unexpected side effects.]

November 3, 2006

[ED: Appt. with Steven. Rita is having trouble eating...throat distress, cough. He recommends “magic mouthwash” a mix of Kaopectate, Benadryl, and lidocaine. And soft foods, smoothies. And suggests that she crush pills. CA 27/29 is down to 81 from 101. The Xeloda is working.

November 17, 2006

Better late than never. My swallowing is less painful. Last night I could eat the Vietnamese soup that Estelle brought. Incredible! The cough is still there. I finished the radiation on Monday of last week - almost 12 days ago. It’s about time. I feel more hopeful. I’m at the end of the first week of the 4th cycle of Xeloda. On December 20th will know if it keeps working.

December 8, 2006

Two days ago I found on the web that the time to recover from esophagitis from radiation is more like 4-6 weeks after the end of treatment. I felt comforted. Less worried, like I am within the limits. But please, please, enough already. One more week of Xeloda. I do feel more energetic, in spite of the cough and pains in the chest.

December 15, 2006

I saw the radiologist yesterday and he gave me Percocet and Mucinex. The pain goes more or less from the spot where the chest tube was inserted to under the breast all around. I think this started around the end of November, early December. Still going on. It comes almost immediately after eating, it's like the food is a "trigger." I have to crack this mystery open. Is it a broken rib? Is it scar tissue that has gotten damaged by the radiation? But what is the connection with the swallowing? Why does it trigger that pain, like burning?

December 20, 2006

[ED from Health notes notebook: 27/29 is down to 55. A slow downturn suggests a slow-growing but sensitive tumor. Rapidly growing tumors quickly respond, but when the drug stops working, they grow out of control and are very difficult to treat. Stay on Xeloda until it plateaus, then switch to hormone treatment. If that doesn't work, switch to weekly low-dose chemotherapy.

December 24, 2006

I saw Steven on December 20th. Numbers are coming down. 27/29 is now 55! Such good news. I told him about the pain on the left side and he suggested the pain clinic at Beth Israel. Now 3 more cycles of Xeloda and then test again, until the numbers plateau and then we'll see.

December 25, 2006

Had a real good time at Connie and Mary Jane's last night, and I could eat quite a bit. I would like for this pain to go away from the back all around to the front. Why didn't my oncologist order an X-ray? Remember: 55 is the 27/29 number and it was 101. The liver is not enlarged!

December 26 & 27 & 28, 2006

I read in the Boston Globe about how a coughing fit can result in a broken rib. Called the oncology nurse to set up an X-ray. My swallowing is much better.

2007

January 2, 2007

For the last 2 days I have been eating without pain when I swallow or on the side. How come? What happened? Sounds too "all of a sudden."

I had a terrible constipation attack 2 days ago. I almost called 911. Finally resolved it.

January 3, 2007

Estelle left for New Orleans. Some pain on the left side of my back this morning, now almost gone! Fede, Layla and me, Sunday to see "The Importance of Being Earnest." And tomorrow night Deval Patrick's inauguration. I feel full of things that interest me!!!

January 4, 2007

Cancer support group at Mt. Auburn hospital. 10 white women from late twenties to me, 72!

January 6, 2007

Deval inauguration party at the Convention Center. I lasted from 7:30 til 1am. I could eat! I did not cough too much. It was so good to have Fede pick me up. We drove, he took care of me lovingly.

January 8, 2007

I had a very bad coughing night. I suspect rice was the culprit.

January 1, 2007

Yesterday I went to a Chinese acupuncturist. He is gentle. Thinks I have a scarred lung. Took my pulse - too fast." Put needles in my legs, arms, ears, forehead and center of head, and some lamps for warmth. I lay down for 30-30" with nice music. He thinks 6 weeks once a week can help the cough. The scarred lung would be a longer proposition. The remarkable thing is that I had a lot of energy, and not much cough, until midnight, and slept a light, dream-filled night with no coughing.

The acupuncturist thinks I might have fibrosis of the lung, diminished capacity to breathe because of the radiation, like scarring, and to do exercise and expand the lung capacity seems important to me now. Will do so!!

January 13, 2007

I am starting the breathing exercises again and will be going to the gym real soon. Maybe even tomorrow!!!

January 16, 2007

Today I ate an orange. Need I say anything else?

I also had my second acupuncture treatment. I find it very relaxing and calming. And it does not hurt; he is gentle. I can't believe it but it looks like the strange pain is gone and I can eat more and more things. Stay tuned.

To try: eliminate dairy; drink 6 glasses of water; go to the gym and walk; homeopathy.

January 26, 2007

A bad night of cough. Terrible cold. Had my 3rd acupuncture treatment. No difference with the cough. Is it my lung trying to reject the stent? I took Mucinex yesterday at 6pm and it seemed to help for a few hours. I could eat a salad and did not cough.

Made an appointment to see the radiologist. My treatment was from October 10 to November 6. Trouble started October 22.

January 29, 2007

Saw the radiologist this morning. Brought in two medical residents to tell them about my case and about my book! He thinks the cough will go away, but suggested I see a pulmonologist; said there are some breathing medications that can help, they do a test and see if it makes a difference. He did think that the stent can be causing irritation. I liked him. I also liked his nurse.

February 22, 2007

[ED. Notes. Every tumor has a growth fraction. 1-2% of the cells are dividing. Chemotherapy gets the dividing ones only. As long as scores stay level, the disease is stable and the tumor is not growing. Remaining tumor cells are there but inactive. 27/29 numbers are stable: 47 on February 1st; 48 on February 20th. Steven thinks the numbers are fine. Explanations for the chest pain: Maybe there are more adhesions. Percocet helps because codeine is a cough suppressant. There might be radiation pneumonitis - irritation in the lung, inflammation. That makes the lung stiffer than normal, and receptors in the lung make you cough when they perceive stiffness.]

March 16, 2007

Too long not writing. Did the Mind/Body course with the social worker, whom I love dearly.

I am better, but not as well as I would like. My liver lesions are smaller. I am still with Xeloda.

Today, doing the dishes, I had an inspiration—do a book called “A Sephardic Childhood” or “Snapshots of a Sephardic Childhood”—with various pieces; My Four Aunts; Running Away; With a Flower in Her Hair; They Arrive, Las Primitas; Jewish Holidays at Aunt Selma; School; Grandfather is Gone; A secret Message Under the Door (check with Alicia); Adoration of Julia [one of Rita’s cousins].

April 5, 2007

Today “they” told me my blood count was a bit low and to postpone the Xeloda and go for tests again next week. I was really incredibly fatigued at the end of the second cycle and even mentioned to Estelle that I would ask Steven to let me have 2 weeks in between cycles.

April 11, 2007

Meeting with Dr. V (covering for Dr. T). I have bronchiectasis: tubes are wider than normal. An injury results in thickening.

I have radiation pneumonitis. It peaks at 6 months, gradually diminishes over the next 6 months.

Prednisone can be used to decrease inflammation. Inflammation will get a lot milder on its own in the next 6 months. Scarring will stay. Early November, last day of radiation therapy, is Day 1 of the healing process.

April 24, 2007

A piece of good news from Dr. V [a lung specialist, I think]. He says that the first 6 months following radiation are the worst; the next 6 months should show improvement.

May 4, 2007

Incredibly good news from Steven: Tumor markers keep going down. 27/29 is now about 38! More Xeloda but I have a 2 week reprieve before starting again. Not going to Argentina in June. A friend asked me, "Are you nervous before going to the doctor?" Who wouldn't?

[From May 4th medical appt. notes: new metastasis in the left femoral neck. Why a new metastasis while the markers are so low? It might have been there before but shows now because it has calcified. Steven does not recommend prednisone because it is hard to get off of. Stay on Xeloda til there's a long plateau. Then perhaps switch to hormone therapy.]

[In this period Rita talks about activism in her journals. Environment. Tasers. Notes on books she is reading. Talks with a woman at Breast Cancer Action. But it's kind of scattered. Wants to call her book *Not Dead Yet: Musings of a Stage IV Cancer Activist.*]

May 29, 2007

[ED. Medical notes. Dr. G, lung specialist. Consult regarding the cough. Lung function is 110%, better than other women Rita's age. There is plenty of capacity there, but there is also a lot going on in the lung as revealed by the scan. Lots of inflammation, the stent, the tumor, the radiation reaction. All of those could cause the cough. What to do? There is no great solution. Tesselon helps some people. If cough does not improve with time, consider a look inside to see how the stent is.

October 10, 2007

[ED: Medical notes. 27/29 is creeping up - to 66. Xeloda is losing its effectiveness. Steven decides to add Faslodex, a hormonal intervention via injection, after Rita asks him about that. If that doesn't work, low-dose infusion chemo.]

December 19, 2007

[ED. Medical notes. 27/29 is stable at 58. Steven thinks the Faslodex is working.

Thursday Dec 20 2007

I am in ecstasy about going to Buenos Aires. It means so much to me, will get all sorts of stuff.

My markers are stable. Steven thinks it is the Faslodex. I am going to get another shot before I leave. Hey, I'll take it. I am 73 and a quarter, heading towards 74, definitely. Steven looked tired yesterday.

Sun. Dec 23, 2007

List of meds she needs to take with her to Argentina

Xeloda

Vit. D3

Propranolol (for head tremor)

Saline solution (maybe for dry nose)

Percocet (for cough suppression and sleep)

Fish oil

[ED Note: Antioxidants supposedly interfere with chemo and Rita was advised not to take them. She consulted nutritionists along the way, including a doctor at Dana Farber.]

Tues Dec 25, 2007

Last night, party at the home of Connie and Mary Jane.

I ate like a piggy. I took a pill of the Mucinex at 4 & did not cough at all. ...I went to bed at 1, too full, coughed, could not sleep for a while, took 1 teaspoon of Percocet, was able to sleep.

Dec 26, 2007

Xeloda: 3x/day for 10 days, 11 days off. On the 31st, Faslodex--It will work!" [ED: Hormonal intervention alone was no longer recommended because of the extent of the recurrence and the fact that hormonal treatments are slow to show an effect. So Steven combined the two.]

I am so thrilled we are going. And that Naomi [Rita's editor at University of California Press] seems interested in the "Ten Years Ago" chapter. I also want to write the review of Melanie Kaye/Kantrowitz's new book and the piece about aunts, which will be great since as part of tia Selma, there will be a section on the "primitas." Get the song of Flory Jagoda about Las Tias. "I have had aunts..."

[ED: We were preparing to go to Argentina. Naomi is Naomi Schneider, Rita's editor at UCal Press. They were about to reprint her book and she asked whether she could add an additional short chapter. They later rejected that idea. Melanie Kaye/Kantrowitz is the author of *The Colors of Jews*, which Rita did review. I don't know whether she ever wrote the piece about her aunts.]

2008

Wednesday Jan 2, 2008

In NYC waiting for a delayed flight to BsAs. Overnight near the airport in a hotel.

My cough seems to be well under control. I wonder if walking helps. I walked back from the hospital [ED: Dec 31], to the National Car Rental [on Mass Ave], and a lot in the airport yesterday. I want to get back into Melanie's book & catch up with Argentina, especially the work about the annulment of the "amnesty laws," how that was done. Use that to stress hope & not giving up."

Thursday January 3, 2008

In Buenos Aires, apartment on calle Beruti

Halleluia. We are safe & sound at Beruti. ...Estelle is such a magnificent companion and trooper! We slept like rocks, she is gone to the gym."

It is soooo wonderful to be able to travel & do things as before, almost. I am truly lucky, like Margaret Atwood's character at the end of Bodily Harm.

My cough has diminished a lot, I don't really understand what is going on, but there is improvement definitely.

Wed Jan 9, 2008

In Pinamar with Ariel and Hilda

Well, what a day. Me bañé en el Atlántico!! 2 veces! Genial. Caminamos en la playa por 1 hora!

Sunday Jan 13, 2008

I am sad UC Press rejected my idea of a new chapter. I have to find another way of continuing to contribute to the work of the Abuelas. Webpage? Ask Naomi if it is possible to add "one line" with a web address, as Estelle suggests. Qué pena. But I will persist with the interviews and continue la difusión de ese trabajo.

I am glad I will get to see Dr. X, it will be more or less like getting a second opinion.

[ED: Steven was taking a sabbatical; we later learned that it was for a stem cell transplant for myeloma.]

I have to start Xeloda on January 17 (I was going to write Tamoxifen).

My feet are so much better. Thank you, Pinamar - Ariel/Hilda. [ED: Walking in the sand and salt water had really helped with Rita's foot syndrome. Ariel and Hilda are second cousins who invited us to spend a couple of days at the beach in Pinamar with them.]

Sunday January 20, 2008

I feel very tired. I think it is the Xeloda, which I started again last Thursday.

Tuesday Jan 22, 2008 – Estelle's Birthday

I am obviously in a supercritical mood, intolerante, "no tolero..." and very itchy literally, last night, I had a lot of itching, it is the Xeloda, I have had that in the past.

I will be happy to get home in one piece.

The ESMA people called to set us up with a visit. Berta's grandson Jorge will be there to greet us (he's working there). "Hurrah! This is really important, thanks, Estelle!" [ED note: I had pushed Rita to get that set up in spite of her tiredness, hence the thanks. The ESMA (Navy Mechanics School) was a major clandestine detention and torture center during the dictatorship.]

Thursday January 31, 2008

[Rita gets back to a swamp of work, indicative of the fact that life went on as her illness was managed...]"Estela Bravo and the Abuelas coming [to NYC] in April, everything coming down like an avalanche. ...Little by little. Keep breathing. There is sun today-Victor Heredia helps-----'Mis Amores'—what a song."

Monday Feb 4, 2008

The Canadians are going to call me about the film they are working on on activism and breast cancer. Call from Canada. Film in research stage= money raised for b.c. and where it goes, european links, & presentation, Nancy Guerin and Patricia Kearns. Nice women!! They will be in touch soon.

Wed Feb 6, 2008

The prep for the colonoscopy was horrible. I vomited at the end, threw away half of the last cup. One 'tiny fold, not a polyp' – will call in a week to get biopsy results.

On Monday I had the blood count & the Faslodex. Today the oncology nurse called to say that I can continue with the Xeloda, the CA 125 is a bit down, the 27-29 a bit up, essentially the markers are the same.

So tonight I started with the mushroom, the Galomeda?, 5 different mushrooms from the same family, 30 drops, I will take just that and see what happens.

Thursday February 7, 2008

I was freaking out because the colonoscopy doctor called & I was put on hold. I was supposed to call her in a week and ask about the biopsy, so why was she calling me? I kept breathing slowly but I was panicky. And then she comes and says, everything was fine, it was not precancerous and see you in 10 years!

I am exhausted.

Tuesday February 19, 2008

I am so sad. My stomach rumbles. An e-mail from Julia saying that Renée is getting weaker, not enough air. Ahhh, it feels too much = Jaime, Laura, Andrea—now Renée & me. We are being castigated with a fury—como dijo Sandra 'tu familia ha sido tan castigada.' [ED: Sandra is the woman whose apartment we rented in calle Beruti. She is a friend of Rita's second cousin Ariel. Laura and Renée are beloved first cousins. Laura

was killed in a car accident and Renee was dying of cancer. Andrea, Renée's daughter had recently died of cancer. Jaime, Rita's brother in law, had also died of cancer.]

I guess a routine that would keep me going would help but with my health as is, the cough...

It all seems too hard. Cuesta arriba.

I am impatient, tired, and angry.

Down, down, down.---How to get better? I feel despondent.

Good days/Bad Days.

I don't want to be pitied.

I take the Roxicet.

Friday February 23, 2008

I have to make plans to go out & some sort of commitment to outside, it really helps a lot. [ED: she had just been out to a talk on the civil rights movement]

Corage, Corage, Corage, Corage, Corage, Corage, Corage, Corage, Corage.

Went to see the herbologist. Left me overwhelmed, too many things, and sugar & cancer. The best part was thinking that the damage in the esophagus is what is really going on.

I am listening to a CD that I really like but I don't know who he is. Interesting.

'Vamos ... yo quiero andar, nunca dormir... Vamos afuera, hizemos banderas,... Vamos, Vamos, Vamos'

Monday March 10, 2008

Yesterday Renée died in the afternoon.

Monday March 31, 2008

What happened? I have not written since Renée died. This tells me something sad & deep. I could not eat for a few days after she died. Then it got better.

Wednesday April 2, 2008

I started writing & thinking. Focus on metastatic breast cancer. Not sure what structure yet.

Hanging in There still relevant and she has a new one *The New Cancer Survivors* & I asked the library to get it for me. [ED: Natalie Davis Springarn is the author]

Today is a good day. Maybe waking up early helps.

Monday April 7, 2008

Dr. X agreed that I should have a biopsy, on Wednesday with a surgeon at Mt. Auburn. Afternoon, 4pm. Estelle can come. Ran into a good friend at Mt. Auburn who also has cancer. Interesting what Dr. X told them: "Partial" remission vs. "Total remission." Side effects, length of the remission, etc. [ED: Rita had a growth on her left

side in the place where the chest tube for the lung surgery had been placed 17 months earlier; she refers to this on April 15th below. Scar tissue tends to be a locale of cancer growth because there is no circulation in scar tissue and cancer cells can grow without the deterrent effects of chemo. Rita hated that that lump was growing and wanted a biopsy and later wanted it/got it removed. Steven had been nonchalant about it, but Rita kept touching it and it reminded her every time she touched it that the cancer was growing, hence the wish to know for sure what it was.]

I had my blood drawn for markers and counts....Counts look OK. Back to the Xeloda.

At 3pm, rBGH call. I hope that we can come to some resolution. [ED: Rita was working on a statement about rBGH with other organizations.]

Saturday April 12, 2008

On Wednesday I had a biopsy with the surgeon at Mt. Auburn. She took a good chunk and it bled quite a bit. Results would be in by Friday she said. Nobody called yet. I am glad I did it.

The Reiki group is useful to me, I can say whatever I feel and nobody gets hysterical.

Tuesday April 15, 2008

The surgeon called this morning: ‘Unfortunately there are cancer cells consistent with b.c.’ and wanted me to go to take out the stitches. She left a message with Dr. X but she was not there. Shit.

Now what? Reading Heart & Soul was helpful, in the sense that it strengthens my belief in my own sense of what is going on. I found the lump and I asked for the biopsy, tired of waiting.

This is a skin metastasis in the place of the scar from the chest tube, the chemo may not be reaching it.

We have to see what the markers are and I have to have a scan or MRI. And I want to talk to somebody who knows about skin metastasis of b.c. not just anybody.

Oh, shit, the point is, what does this mean in terms of overall disease? Is this a general flare up or an isolated episode. I definitely have tingling and numbness in my hands, not so much in my feet. Very sensitive to cold.

Apart from this I am doing quite fine!! Poor Federico, Mario with prostate & me with b.c.

I am glad I have the Reiki group to share my bad news.

Roller Coaster time again.

[ED Medical notes, April 15, with Dr. X: The mass in the liver is growing again. In Feb 2007 it was 5.9cm x 4.6. Is now 6.3 x 4.5. Dr. X recommends a tougher, IV chemo because liver metastases are serious. There is another pill chemo but it damages bone marrow and if there are further chemos, they would be harder to tolerate with damaged marrow. Recommends Gemcitabine. Said it works fast if it’s going to work. After 2 or 3

cycles (3 weeks on, 1 week off), new CAT scan. And stop the Faslodex since it isn't working. The tumor is Her2 negative, which is good. Is it true that hormone sensitive tumors don't respond to chemotherapy? Yes, but not in the case of metastatic disease. According to the CAT scan, lung is stable and the inflammation from the radiation is healing. There's a new lesion in the liver. The other liver lesions seem stable in size. There might be a new lesion on L2. What about the little lump on Rita's left side, the one that was biopsied and found to be malignant? It can be followed via physical exam. There is no immediate harm so there is time to consider what to do about it. What about Vitamin D and fish oil and a multivitamin? There is no evidence that these help. Don't take large doses during chemo. If take them, take them during the week off.

Sat April 19, 2008

Yesterday, met with Dr. X. Bone scan and CAT scan next week, then we'll see what treatment is appropriate.

CA 27-29 up a bit about 69.

The surgeon took out my stitches.

Dr X thinks we should leave the lump in place as a marker.

We went to Beverly, to the "raw food" restaurant.

Sunday April 20, 2008

Mama mia. The film "The Truth about Cancer" by Linda Garmore knocked me over. I taped it last night at 12. David Ryan, a friend's doctor talks a lot in it and the issue of Phase I clinical trials was there. This patient died after all. And he is young, very committed, etc., long interview with him also in the pbs.org page.

Many deaths & recurrences. The breast cancer patient hanging in there after many treatments. Makes you happy to get "just breast cancer."

Nothing about insurance or costs of all the drugs & procedures.

Is my cough because of the tumor, the stent or the radiation? Or a little bit of each?

Is the tingling in my hands, mostly in the right one, because of tumors pressing on nerves, or because of peripheral neuropathy, and also hand & foot syndrome. The scans will give a clue.

I am impressed with Dr. X & the speed with which she moved. I wonder if Steven is going to be back & if so, when. A lot to think about.

The movie was quite devastating. It is the first serious movie about cancer that I have seen on TV, about research and patients also, and offering a grim picture. I like the emphasis on "not blaming the victim," that it's all about biology and not what he/she did wrong. The husband seemed like such a good human being. And they had a great relationship and were in the prime of life. This is what happens.

It made me think a lot about my long history. I have been very lucky.

As one of the panelists put it, "death is not optional," it will come to everybody. I just probably know what I am going to die of. The question is when and how.

And enough now about Cancer. Back to the abolitionist William Lloyd Garrison.

Tuesday April 22, 2008

This book seems worth looking into: *I heard the vultures singing: Notes on Poetry, Illness, and Nature* by Lucia Perillo. San Antonio, Texas, Trinity University Press, 2007.

Wednesday April 23, 2008

I am very happy.

Write about “not getting old.” One of the side effects of getting cancer at 39 was that I never worried about old age. I never thought I would make it over 50 or 60 at the most.

I did not pay attention to retirement, old age health issues, pension plans, age discrimination. I just thought I would not be there for that, so why prepare? It first hit me when I was 55 and started getting AARP materials inviting me to join and learn about this or that old age issue. Who, me? Whom are you talking to? When it dawned on me that this was something to take seriously personally and started to do so, I was overwhelmed. Health insurance, which I had through my teaching job, would end if I stopped working. I realized that there was no “early retirement” for me. No one would insure a woman with metastatic breast cancer. Medicare was my only way to have insurance. Luckily I liked my job enough and stayed on until I was 70 when myself and a whole group of long-term faculty were “let go” by a new administration, unceremoniously, in a “coup” that destroyed the institution we all worked so hard to build over 35 years.

Since I kept working after 65 I did not have to deal with the marginalization that many older folks suffer when retiring and the loss of structures and community that goes with it.

When the moment came, at 70, I had enough other projects to keep me involved and interested so my transition into “Jubilación” was not as hard as it may have been otherwise. I had more time for myself, reading and writing, doing political work, but also more time to notice the subtle and not so subtle ways in which I was now even “A little old lady” (yes, I am short, too) feminist activist in the 21st century, amid young feminists and middle aged ones too, with a terminal disease. Not exactly the most attractive picture. But what the hell, I had survived long enough with a cancer spread, so I knew that what does not kill you usually makes you stronger. Or is it that something that almost kills you makes you stronger? Whatever. (Nietsche?)

Oh, well, death and aging are not optional. If you are lucky, you will have to deal with aging, and as for death, that is not optional either.

Saturday April 26, 2008

Yesterday, oh, what a day. CAT scan and bone scan in the morning. After bone-scan, went out to my car. Gone- towed because of street cleaning. Back at 3:30. Dr. X had the CAT scan, the liver lesion has grown to 6.3cm (it was 5.9) so now to infusion therapy, once a

week for 30 minutes. After three weeks, one week off. No hair loss. Major side effect possible: low white blood cell count, nausea. It's an antimetabolite. Gemcitabine.

Maybe also a lumbar metastasis? No bone scan results yet.

Well, I am eager to try something that knocks the tumor down for a while.

April 28, 2008

First Gemcitabine treatment. Intense, for all the things they throw at you—nausea and constipation seem to be the biggest possible side effects.

All these drugs, today I am supposed to take Compazine tonight and tomorrow morning to prevent nausea. The other pills are taken the day of the treatment, before getting the Gemcitabine.

They took X-rays of my left pelvis and leg, new metastatic disease, could be prone to fracture. Scary. There is also a new vertebrae involvement.

And it seems there was some pleural effusion?

11pm no nausea. Took the Compazine at 6pm. Take again tomorrow morning at 8am.

Wednesday April 30, 2008

Horrible constipation... finally addressed.

Dry mouth, definitely, from Compazine?

All these medications... it is impossible to remember their names, what they are for, side effects, take with food or not, interactions and complications, etc. I have Compazine (for nausea), 2 things they gave me in the hospital (Zafron and Dodecadron), a laxative (Sennet?). Is this all? Drives me nuts.

Thursday May 1, 2008

This morning, no constipation. Maybe they gave me too much Compazine. I have not had nausea; maybe I can do with less and avoid constipation?

Cambridge Naturals put our open letter in their electronic bulletin. Great connection!! It goes to 2000 people! Yipee!

Monday May 5, 2008

Second Gemcitabine treatment. Leave the past behind.

Today: The shock of my life: Steven had multiple myeloma, his head was shaven and he looked well but thinner, had a stem cell transplant, one month in isolation at Beth Israel. Had thalidomide. WOW. It is going to take me a while to digest this one.

Saw Dr. X, not to worry about the left femoral stuff, go to the gym again.

I will take Compazine tonight, the nurse eliminated one of the pills responsible for constipation (Zofran), take also 2 Senna tonight. If no nausea tomorrow, do not take anything else.

Tuesday May 6, 2008

No constipation, so I am not going to take Senna, and no nausea, so I am not taking the Compazine.

I was awake all night and could not sleep. What is it, the Compazine, the Decadron, or the Gemcitabine?

Wednesday May 7, 2008

I slept well.

May 10, 2008

Tired but fine.

Monday May 12, 2008

Today, last treatment of first cycle.

No treatment today because of low platelet count. Go next week. 2 weeks on, one off. Careful with bruising, cuts, etc.

Wednesday May 14, 2008

I think I am starting to lose my hair.

I went to Pathways to Healing in the South End and got a couple of acupuncturists' names.

Thursday May 15, 2008

Soon they are going to call me from Radio New International News from Australia [ED: to interview Rita about the Grandmothers.]

Tuesday May 20, 2008

Yesterday I had chemo, platelets back to normal. No nausea. Took 1 Compazine, reduced Decadron, one Compazine at night. That's all.

Today, bought a wig at Beth Israel. Not so bad. Nice woman. \$140.

Things are going well with the Open Letter. Boston Open Media, Our Bodies Our Selves, Alliance for a Healthy Tomorrow, and Massachusetts Breast Cancer Coalition said yes, also.

Thursday May 29, 2008

Absolutely rotten day. Too much talk about cancer. C,C,C,C

Slept at Estelle's, morning went to acupuncturist. I liked her a lot. Came home pooped, went straight to bed. Exhausted.

Symptoms:

- Tingling hands and feet
- Like a vise on my head
- Cough
- Hair loss, but less
- Dry mouth

- Dry lips
- Hands still red from Xeloda, looks like eczema
- I am very tired

[ED: Many people in her circle have cancer. Rita names 7, including her oncologist.]
Cancer Sucks says Breast Cancer Action's button.

I e-mailed Ralph Moss [ED: a resource for alternative treatment approaches], he answered. He mentioned a Dr. Simone or something who seems to be close to the "endobiogenie" model. Will check him out.

Can I live this way? Is it worth it? Is it going to get better or worse?

Sunday June 1, 2008

Yesterday, a lovely time with friends at Estelle's house. But I had a lot of pain in my left side, especially when I coughed. Tylenol helped, 2 tablets every 6 hours. Broken rib? Liver metastasis? In the 2006 bone scan they saw metastasis in the first lower rib. I feel calmer in spite...

Tuesday June 3, 2008

I had a rotten night. Yesterday I did not take enough Tylenol so it hurt. Also Marilyn French's book, *A Season in Hell*, got too depressing—her long chemo stays in the hospital, sharing the room with other sick people, the emergency room, etc. It was too much. Not the right thing to read. I emailed Dr. X a clear message, telling her what is going on, cc to Estelle.

Reading Marilyn French's book I loved/envied her friends and the wonderful support she got from them. And as I was feeling so lonely and burdened, was glad that I emailed Dr. X, cc to Estelle. Actually, 5 minutes afterwards, a friend called and instead of ignoring the call, I answered and told her what is going on, all of it. What a relief. This was really helpful.

It took me a bad night to know what to do and act. When will I learn? I have to be more expressive and assertive all the time. I am always afraid to scare others and trying to protect them. I have to find the right balance but I am not quite sure of what that is.

With my hair falling out, the neuropathy, the pain in the 'rib,' I am a physical wreck & need to do something to get out of this low mood. But I don't know quite what. ... Well, at least I emailed Dr. X and I talked to a friend & Estelle.

Wednesday June 11, 2008

Roller coaster. I have a fungal infection in my right ear, mostly. I had chemo on Monday, I am anemic, they gave me an injection.

Dr. X. does not think I have a broken rib. My hair stopped falling out. I have hats and handkerchiefs.

I am down to just one Compazine with the chemo. That's all.

Today I start acupuncture. I like her.

I wrote "How my story began." I will keep working on this.

Looking at my old diary. Boy! Was I confused and lost about men in my thirties. What luck I've had meeting ESTELLE!

Monday June 16, 2008

On Saturday night, horrible coughing fit at a public dinner. Very demoralized.

Marilyn French's book is so depressing. I am tired all the time.

My hair stopped falling out. I am a wreck. The good thing is I started acupuncture last Thursday.

Today the Gemcitabine "infused" – big blob, itched, ice. They had to use the other arm (18 lymph nodes were removed 34 years ago).

Tuesday June 17, 2008

I found the old Science for the People issues. I used them to write about what was going on in the 70s for me. Also mention New Words bookstore opening, 2 months before the diagnosis. Complicated, but worth trying.

Wednesday June 18, 2008

Saw Steven today, got his e-mail and made plans for a barium swallow, and to see Dr. G next week for the stent issue. [Dr. G is a lung specialist.] Maybe also an endoscopy.

Today was a very bad cough day. God only knows what is going on. One marker had gone up 10 points, then came down 10 points. We'll see. More Gemcitabine for now.

Went to acupuncture. Read some articles about artemisinin (from wormwood).

Friday June 20, 2008

Not too bad a day.

I am ready for Chapter 3, "A cough that would not go away."

Monday June 23, 2008

Had a bad cough day. I am relieved I am moving on the cough: Tomorrow Dr. G and Thursday, barium swallow.

I am thinking maybe of shaving my head. "Anna" would do it or cut it. She lives near Mt. Auburn Hospital. [Note from Estelle: Anna is a pseudonym for a cancer patient and beautician who cut breast cancer patients' hair gratis. We went to her house and I photographed her cutting Rita's hair and trimming her wig.]

Hair – Itching – Cough – Cancer—I am a wreck, but I am not ready to die yet.

The marker went up after 2 Gemcitabine treatments and came down after two more treatments. So if it keeps going down it would be a victory.

Wednesday June 25, 2008

Yesterday we saw Dr. G. My breathing capacity is totally normal for a woman my age! That's the good news. The bad news is he doesn't think he can help me get rid of the

cough. He will talk to Steven. There is some wheezing, some constriction, the prednisone won't help now, the pleural effusion is minimal. It all reinforces the upper GI connection problem. I will investigate diet for ulcers and GERD.

Well, at least I won't need an oxygen tank soon...Celebrate—

Thursday June 26, 2008

Barium swallow. Estelle took me at 8am. Quite horrible, drinking barium. I was dizzy at the end. I felt demoralized. Did not cough during the procedure.

Monday June 30, 2008

Today chemo at 2:30 and hair cut at 1:15. I have a draft for Chapter 3.

Tuesday July 1, 2008

Things are moving. Yesterday I had a terrific haircut with Anna in her house. Great help. The chemo went well, there was no trouble finding the vein. Steven got the barium swallow report. I have a narrowed esophagus and need an endoscopy. I just called Dr. C and she is going to see me at noon today! They first said September 30!

Things are moving. Marilyn French was right! Keep at it, keep at it, keep at it, keep at it, keep at it, keep at it. Don't give up yet...I feel I am on a path to something.

After seeing gastroenterologist Dr. C: She is concerned about doing a dilation on a "brittle" esophagus, and what if there is a fistula between trachea and esophagus? She wants to consult with Dr. Q at Beth Israel who is her doctor and took care of her mother. Also gave me a prescription for something to control gastric reflux. She does not want to do more harm. Will call me next week.

I feel relieved and well taken care of. Also, I took the pill 30 minutes before lunch and I coughed less. Or is it a fantasy? We'll see. Give it a few days at least.

Tuesday July 8, 2008

We had a great time in Eastport. The pill from Dr. C helps.

Today: BAD News. All the markers went up. CEA from 5.7 to 6.8. CA 27/29 from 66.9 to 93.3!! Steven did not show up. Sent a message that I am to do two more treatments of Gemcitabine: 'You have not had enough of this chemo yet.' Well, how much is enough? I am demoralized, angry, & scared. How much is enough? Also, he could at least show up to explain the rationale. Too much today, too much bad news, all in one day. Don't know what to do. Change doctors? At this point? And to whom? They all more or less think alike. Change hospital, it all feels like too much to deal with.

Wednesday July 9, 2008

I sent an e-mail to Steven! He answered: will do a CAT scan, etc.

Friday July 11, 2008

Coughing again

Yesterday at my Reiki group, recommendations: slippery elm gruel, DGL, mastic gum and Mattress Genie to elevate the bed.

They also suggested a nutritionist at the Marino Center who works on gastric stuff and can wean a person from omeprazole (that is what I am taking) onto something healthier. My acupuncturist said that these drugs rob calcium from the body, increase blood pressure, and eliminate beneficial bugs from the stomach. So watch out.

Saturday July 19, 2008

Too much going on.

Monday July 21, 2008

CAT scan showed disease progression in the liver. Change to Abraxane.

Steven gave me a lecture about weight and eating. Liquefy, sip, etc. I need to gain weight. He is calling Dr. Q about an early appointment. That would help. I am calm. Worried/relieved that we are changing chemo. Abraxane is a taxane (Pachitaxel and albuminil).

I am seriously considering a port.

I hope the Abraxane works.

Check the Leonardis Clinic. I just did! Great testimonial from a prostate cancer patient, and then in Annie Appleseed's page, a notice that that patient died, 2 years after the great testimonial. How depressing, the whole thing.

[Note from Estelle: Rita took charge. Did not wait through 2 more cycles of Gemzitabine. Insisted on a CAT scan and that prompted the change of chemo. There were no hormone options because they work too slowly and liver lesions are trouble.]

Friday July 25, 2008

Next Tuesday, endoscopy at noon. I e-mailed Steven about it and to set up a date to start Abraxane. I get a message he is out until August 11. I was furious. I called one of the oncology nurses and she will set it up with Dr. X.

Yesterday when Estelle was here I had a terrible coughing fit. I can't live this way. E. gave me Mylanta, that calmed it on the spot & I slept well. It's as if my guts were coming out of my mouth. HORRIBLE

Now I am going to the health food store to check high protein drinks, bars, etc., things to make smoothies. I am determined to get weight on, one way or the other.

Acupuncture comforts me.

Monday July 28, 2008

Article in the Globe about GERD and lungs. It fits.

A gift from the Cosmos: Mary Kirk's review of my book in *The Feminist Teacher*, Vol 18, #2, 2008!

Wednesday July 30, 2008

After the nightmare.

On Tuesday morning (July 29) we went to Beth Israel hospital for an appointment with Dr. Q at noon; got there at 10:30. We finally saw him at about 3 and I decided to have the endoscopy and dilation, no stent at this point. I liked him, and he was totally reasonable.

I had the procedure at 3:15, don't remember a thing. He did biopsies, dilated the esophagus at 1.8 cm, the hiatal hernia should not be a problem, and suggested some antacid meds if needed. Gravity, he said, should help with the acid reflux. Mylanta is O.K. and will not become ineffective or cause complications.

I came home, chills and a 102 fever. Estelle called Dr. Q and they said to go to emergency. It was about 9 or 10 pm. Shit. We went, my own room, a mask, and the procedures would be intravenous antibiotics, chest X-ray, and CAT scan. For the fever, also Tylenol. Hours waiting with Estelle at my side and lying on the floor.

The CAT scan was a horrific experience. I had to swallow 6 spoonfuls of a paste (like toothpaste, literally) because after 3 spoonfuls, the radiologist wanted to repeat the test. And I was desperate to pee. I told them so. She did not want to move me because I was in the "perfect position." They left me alone in the room. I screamed twice, "Is there anybody in this room" – no answer. I was dying to pee. It was pure violence. And how I managed to swallow the paste is a miracle to me.

Back to my cell, after hours waiting, the emergency physician who looked like a teenager, comes and says the CAT scan is uneventful, not much different from a 2006 scan I had after the bronchoscopy. But the radiologist was saying that to be 100% sure that there was no tear I "should" maybe have a fluoroscopy. There is debate about it. Nobody knows. I refused it. The doctor said, "You have metastatic breast cancer. You can do anything you want!" Sacred words. He agreed to discharge me, first with no prescription, then he came back and said to prevent pneumonia he would give me something. Levaquin is the prescription, 250mg.

I felt he had fully agreed with my decision and now I think the radiologist had me take 6 spoonfuls because she was unsure of her work and the fluoroscopy was more of the same.

We left B.I. at about 4:45 am, got home, threw ourselves in bed and I could not sleep.

I forgot this: Dr. Q said that I should wean myself slowly off of Roxicet. I had not taken it since Monday midnight. Estelle thinks I was in "withdrawal." I was hyper, that is why I could not sleep.

While at B.I., the fever started to come down to normal, from 102 to 98.7. I visualized the numbers coming down, 102, 101, 100, 99, 98 to give myself strength and hope. And I started saying to myself, all will be well, this is just like 2 years back when I had the bronchoscopy, had fever and chills, and it went away on its own? (or I was taking antibiotics that they gave me when they discharged me?). I think I was.

So now I am taking Roxicet less, ½ teaspoon morning and night for one week, then 1/3 teaspoon for another couple of weeks, etc.

I had a smoothie and some solid food (eggs, bread, watermelon). Very little cough. I think the dilation helped.

Marcie called. Dr. Q had called her. She wants to see me before the weekend.

We spent about 6 hours in the emergency service. I did not have any food or water for about 30 hours.

Wednesday August 6, 2008

Yesterday, Abraxane, first treatment. 4 treatments then a CTscan.

Wednesday August 13, 2008

It has been good in Wellfleet. My cough under control. The lump on my side feels more or less the same, maybe shape has changed?

When I get back, check my old diaries and “do” Bolivia. [ED: Rita is referring to writing about her choking episode in Bolivia as part of her cancer story.]

I am afraid to be alone the 10 days that E is going away [ED: to Newfoundland] but I will do it. I have to. I can't have her take care of me all the time. I have to work on my attitude and on my hope and strengths. The improvement of the cough is just unbelievable. The quality of my life has increased 100%. If this could happen, anything can. Think positive, speak up, get what I need. Soon I will be 74, a respectable age. Estelle got to do a lot of reading for her course while in Wellfleet. Thank God for her stability & strength.

Abraxane has to work! I am going to read about how it works and create some visualization scenes. Taxol and albrumine. Read about Taxol. Yesterday I walked quite a bit. I am glad the summer is coming to an end. [ED: For a heat-lover this is an unusual comment from Rita. I think the medical issues were so difficult that she just wanted that summer behind her.]

Sunday August 17, 2008

I had a bad night. I think it was the peppermint ice cream, too much of it.

Ordered an inflatable wedge pillow. And a book about GERD. I have a lot to learn. The radiation damaged my esophagus, that is for sure. The acid reflux may be connected or not, but now is there. I had a chocolate Ensure chilled, like Marilyn French. I am reading her book again. I need to find something non-cancer-related to read.

Please, please make the Abraxane work I want to understand more about the microtubules[?] and how it may work. My lump on the side feels more or less the same in size but maybe different shape. Abraxane, please work!!!

Friday August 22, 2008

A lot going on. Fede was great at chemo. Also on Wednesday I walked 2 miles at Fresh Pond. The lump on my side is more or less the same. I am losing a lot of hair. I feel quite well, though last night after an event I was pooped, came home and got to bed at 10pm. Slept a lot.

The metastatic breast cancer movement is growing. I should try Governor Deval Patrick and his Health Commissioner Bigby. I am working on the Cambridge Health Alliance. [ED: This refers to an effort to establish October 13th as Metastatic Breast Cancer Awareness Day. Rita was lobbying various groups for support.]

I must start writing again- La Paz.

Monday August 25, 2008

Went to Mt. Auburn cemetery with Fede and climbed the tower! 95 steps! I could not believe I did it!

It feels like my lump is a bit smaller.

Thursday August 28, 2008

I think I have shingles. I am demoralized.

Friday August 29, 2008

I saw Marcie and she gave me Valtrex, an antiviral drug. She called this "a minor hurdle." Big pills, 1 gram, 2x/day with food. I called the pharmacist to see if it is OK to crush the pills. She said yes.

I feel the lump on the side is bigger, like there are two now.

Sunday August 31, 2008

My shingles do not ache but burn a bit.

Tuesday September 2, 2008

I had my third treatment with Abraxane. My shingles responded to treatment!

Thursday September 4, 2008

Yesterday, terrible constipation attack.

I am demoralized= constipation, shingles & cancer lump looks like double, growing. How do I pull through all this?

Friday September 5, 2008

Yesterday was a horrible day, I was scared, grumpy & resentful. Estelle & Lucky came over. It helped a bit. I started a multivitamin. I am thinking seriously about Chinese herbs now.

Saturday September 6, 2008

This morning I thought the lump was smaller. Now, not so. Grey Day. I am stuck. This is the worst challenge of my life. Still shingles, no constipation. I resumed writing. On Tuesday I will be 74. How much longer am I going to live? I will not ask Steven. He doesn't know. My recurrence was in 2001, when I started Arimidex.

Tuesday September 9, 2008

74th birthday

I called the oncology nurse & told her about total exhaustion, tingling in the head, no energy, etc. She talked to Steven and tomorrow morning I am having a CAT scan of the head & afterwards a check on my blood for anemia, etc. Well, at least this is soon.

I got the Compassion and Choices newsletter yesterday. Is this a signal of what is coming soon? Hospice?

If I do have brain metastasis, what to do? The treatment could be worse than not doing anything.

Wednesday September 10, 2008

No brain metastasis! And my blood is OK! Seeing Steven Friday at 2:15 p.m.
RELIEF!

Friday September 12, 2008

Points for Steven:

- (1) Markers since Abraxane
- (2) Lump on my side
- (3) Tamoxifen added?
- (4) Argentine Arimidex [ED: Rita bought Arimidex in Argentina at a greatly reduced price. Later many drugs were identified as phony and she wondered whether that might have been the case for her. Steven later said that he looked up the countries where false drugs were being sold and that Argentina was not one of them.]
- (5) What next?

I found a new book, *Anticancer: A New Way of Life*, by David Serban-Schreiber, Viking Press. Just out here. Out in France last year.

[ED: Notes from the visit with Steven. (1) Regarding Markers, it's too soon to tell. Sometimes they go up before they come down. (2) Fluid in the body can affect lump size if it's fluctuating day to day. (3) He'd consider adding a hormonal treatment if the marker numbers plateau, but he wants to first see whether the Abraxane is working.]

Tuesday September 16, 2008

Today, 4th treatment with Abraxane. Lump the same, more or less. I think Steven has been evasive about markers. I feel like letting him try the Abraxane twice. I finished *Anticancer*. Very good. I will review it for Cambridge Naturals. I will try to exercise & eat more. I will make a serious effort...

Sunday September 28, 2008

Meditation, my own way, I need to do something to calm my fears...I ordered the Weil/Zinn tapes. I tried to do 15' this morning.

Get my mind off cancer for a while. I sent my op-ed to the guy at the Globe on Friday. The lump is still there.

Monday October 13, 2008

Metastatic Breast Cancer Awareness Day

Tomorrow is the last Abraxane treatment and the lump has grown. Serious talk with Steven. Can I stop chemo for a while & rebuild my strength before trying something else. There is a woman in Newton who had aggressive chemo and her liver metastases regressed.

Tuesday October 14, 2008

Oh! A nasty review in the NY Times about *Anticancer*, sarcastic tone, who needs that? My only regret in my review of *Anticancer* is that I didn't say more about "the cancer personality" controversy.

Thursday October 16, 2008

The lump is hard & bigger. I looked at the chemo that the woman from Newton had & it causes cancer. I felt very low. I did go to the gym.

Friday October 17, 2008

Hard times. I was panicking about going to Wheelock College next week. Thank God for Estelle. Jon Margolis accepted the op-ed for B.C. Awareness Month, for October 27! It gives me hope. I went to the gym. [set up a Link to the op-ed]

Monday October 20, 2008

We went to NH Sat & Sunday. I had a bad night there but in the morning Estelle helped me think & now I have a draft for an e-mail to Steven. ...I am going to fight.

Wednesday October 22, 2008

Yesterday a colleague in WCCP and I did the Stonewall lunch at Wheelock College, on "Contaminated without Consent." ...It went really well.

Fede came & I showed him everything: the letter to Steven, Estelle's message about herbalists, etc. He was great....I am sending emails about my op-ed.

Saturday October 25, 2008

I met a breast cancer patient with whom I'd been talking by phone. What a breath of fresh air and warm energy. She now has one metastasis on the liver but it is small and they are going to freeze it. I will get a second opinion from her oncologist.

Monday October 28, 2008

Saw Steven today. As I expected, the treatment did not work. So, he did not say 1 word about the book [Rita had given him a copy of *Anticancer: A New Way of Life*] and he didn't like the idea of Chinese herbs. I have a 1-month break before I start with Doxil which looks quite heavy. He always minimizes the side effects—Heart Damage? I am too tired now. I was expecting worse news, so I have been stressed by the uncertainty of it all.

[ED: Additional Notes from that appointment. It's OK to remove the lump on her side. Antioxidents protect cancer from chemo and radiation in lab cultures, so he is cautious about them. Make sure whatever you take does not have estrogen. David Avigan works on tumor vaccines. Steven will ask him about their use in breast cancer. How about relating to a close friend who has MRSA? You can be around her but don't touch her or her stuff or be near her if she is sneezing. Wash your hands.]

Tuesday October 28, 2008

So many messages about the op-ed. [add link to op-ed here also]

Wednesday October 29, 2008

I will have my heart checked with Marcie. Steven sent me the "vaccine expert" answer but with no comment at all. How to deal with the second opinion issue is an issue! Also, he didn't say anything about cutting the lump. Do I need a referral or I just call her myself?

He does not communicate real well. I think he got complacent with my case. If he had scheduled me for checkups every 6 months I would have gone & maybe the liver metastases would have been smaller & could be removed by freezing or burning.

Friday October 31, 2008

Ordered 2 Ralph Moss reports. [add link to Ralph Moss, above also] Yesterday, at acupuncture, difficult talk about Steven's opposition to herbs. I am going to try to gain weight & do good things for myself!

Monday November 3, 2008

A lot going on. Servan-Schreiber remembered seeing me in the French film, "The War on Cancer." Sent me his article from the International Herald Tribune. I sent him mine first. [ED: I think Rita send him her review of his book.]

Will try artemisinin & Dr. Weil's immune booster, astragalus + mushrooms. Got an email from Sylvie from France. Things are going well with them. [ED: They are the directors of The War on Cancer. We had lunch at their house in Paris last time we were there...lovely people.]

Tuesday November 4, 2008

I voted at noon. My back hurts a bit, from the fall, 2 days ago, in the porch.
[ED: health notes: weight down to 103.5]

Wednesday November 5, 2008

Obama won! Paolo died, Federico called.

Yesterday, we saw Marcie . I told her about my communication problems with Steven. She said he is afraid of losing me, etc. I pointed out 2 medical errors, not following me every 6 months & forgetting to order scan & blood tests for last appointment. No answer from vaccine doctor. I called [the oncologist at MGH with

whom Rita wanted a second opinion] for an apt. She wants pathology from first surgery and most recent treatment plans. Marcie M. called back, she spoke with Steven who said he had not received her messages. He sounded “edgy.”

[ED: Journal notes include learning that records at Cambridge Hospital go back only 20 years, but they will send a form anyway; Rita never did get the pathology report from her original surgery 34 years earlier.]

Saturday November 8, 2008

I think my back is better. I started yesterday again with the omeprazole, will see [ED: aka Prilosec, for GERD]. I have to gain weight. I am eating more. Is my esophagus narrowing again? On Tuesday I am having the lump removed and on Wednesday an echo on the heart. Wrote to Abuelas and others in Argentina about not going [to Argentina in January].

Got the Ralph Moss report on Boston area alternatives. A couple of plans seem interesting. I just finished hearing an interview with a local naturopath and I am impressed. Does blood tests to check immune system and what works or not. I will see him.

Acupuncturist called. The artemisinin is in.

Sunday November 9, 2008

Second day taking artemisinin.

Yesterday night was horrible. I had a coughing fit talking with a group of colleagues by phone. I feel very demoralized. Estelle lifted me up and we went to the deCordova Museum.

I am eating more.

Tomorrow:

- (1) call Cambridge Hospital
- (2) call Clinical trials at UMass
- (3) Call Marcie’s office about getting the drug that Dr. Q suggested
- (4) Call the naturopath

Monday November 10, 2008

I called Cambridge Hospital, they only keep medical records for 20 years. Will send me a research form.

Got an appointment with the naturopath for Friday.

Went to the gym. Faxed form for clinical trial conference

Tuesday November 11, 2008

Appt. with nutritionist at Dana Farber.

Today was crazy. The surgeon did not remove the lump and will do it when she puts in the port, in the operation room, next week. [ED: Rita had assumed that the lump would be removed in the office. She had had a previous small lump removed from her shoulder in the office of a different surgeon years earlier.] When I get home, a call from

the Echo-cardiogram folks, the machine is broken, so nothing tomorrow, maybe Thursday. No date yet for the operation.

Thursday November 13, 2008

Went for the Eco-cardiogram.

Got the form to ask for my original pathology from Cambridge Hospital. Have to do that.

Tuesday November 18, 2008

Yesterday and today totally crazy. Yesterday: I went to Mt. Auburn for “pre-test” and registration for Friday’s surgery and called Rational Therapeutics in Long Beach, CA. Spoke with someone who seemed competent, would send the kit. [ED: Rita decided to have her tumor tested for resistance to various chemotherapies in hopes of getting help assessing which one(s) might work. That was suggested by the naturopath. That required packaging the tumor sample in a particular way and sending it via Fedex.

Today we went to a lab in Lowell, for the blood tests (15 tubes!) and stopped at the naturopath’s office to pick up pills. They did not have the Pyenogenol.

Then, nasty phone conversation with the surgeon. “You have to choose.” “Mt. Auburn protocol.” “Can go to another hospital,” etc. Then I spoke with the pathologist, more rational, said he would do his best. [ED: His best meant to save as much of the tumor as possible to send to Rational Therapeutics in California. Rita was concerned about how much would be available for the testing and called Rational Therapeutics to ask about priorities if the tumor sample were too small for all tests.] Got the kit from CA.

I need to work on the materials for [ED: the second opinion doctor]: pathology from first surgery, most recent treatment plans/CAT scan/bone scan and reports. Date to see her: January 8, 2009.

I saw my holistic physician this morning. Supplements and Iscador. [ED: Iscador is a homeopathic injection that has been used in Europe for decades.]

Teeth also!!! [ED: Rita had a loose bridge that needed replacement, though she never got to do it.]

I can barely keep up with all the appointments and changes. I don’t know how I’m going to do all this. Truly, I don’t think I can travel anymore with all these supplements and Iscador.

Saturday November 22, 2008

Yesterday I had the port put in and the lump removed from the chest wall. The pathologist was great. I met with him before the surgery and explained everything. He got it and agreed with me on the report and thought he could have enough cells to send.

My Reiki therapist was very helpful in telling me to thank the surgeon in order to heal from the nasty phone conversation we had. Fede took me to the hospital and sat in the waiting room. Met the pathologist also. When I got out Estelle already had the box in her hands and we went straight to FedEx. So it worked! I could never have done all this without Estelle.

I slept OK, some pain. Estelle got me Tylenol with codeine.
Today I started the naturopath's supplements. We'll see how it goes.

Tuesday November 25, 2008

Today I go for Doxil, first treatment. Steven knows about the CA thing, he doesn't think much of it. I started with the naturopath's supplements, it could be worse.

Wednesday November 26, 2008

Started Doxil yesterday. The port works. Yesterday and today no naturopath supplements. I want to see how I feel with the Doxil in terms of nausea, side effects, etc. Fede took me in, Estelle came in. Steven did not show up. Went right to bed afterwards. Estelle did laundry and shopping.

Saturday November 30, 2008

I hope the Doxil works. Taking pills...

Tuesday December 2, 2008

Yesterday I got the report from CA. My tumor is resistant to a whole bunch, only "intermediate" to 2 things. ...Bummer. Estelle was great yesterday when she heard the bad news. Talking about death, etc. ...Federico came over and we had a lovely and intimate talk.

Today, 2nd Doxil treatment, no naturopath supplements today and tomorrow, just like last week.

Thursday December 4, 2008

Naturopath this morning! 90 pills of something. Change of supplements because of the Doxil and the results of blood tests. Overwhelming. I am spending all my time dealing with cancer. I hope the Doxil works. The timing, the sequencing, the whole thing is crazy-making. [ED: The naturopath prescribed 90 tiny capsules to be taken before bed. There was no other form of that supplement available. When Rita complained, he said she could open the capsules and mix the powder with apple sauce. Rita's hand-foot syndrome had rendered her hands less functional. There was no way she could open 90 tiny capsules. I could have done it but she pretty quickly decided against the naturopath's approach.]

[ED: On Dec 10 Rita started Iscador injections. This is reported in a different notebook; that date is not mentioned in her journal.]

Tuesday December 16, 2008

A lot has happened. I dropped the naturopath, got a refund [for unopened bottles of supplements]. It was impossible. I am working with my holistic physician, Iscador and other things.

I feel better. I got a juicer from a friend.

Monday December 22, 2008

This morning I drove myself to the holistic physician's office [ED: with lots of snow around]. Was there on time! Points on the back and 20 minutes with heat machine. Got the Iscador from her and also from Germany today. Saw the acupuncturist. She is GREAT. Tonight, Iscador with Estelle. [ED: I help Rita with the injections because of her fine motor difficulties.] The holistic physician suggests avocado, seeds, and nuts.

Sunday December 28, 2008

I continue with Doxil, is it working? Homeopathic pills helping cough.

2009

Thursday January 1, 2009

[ED: Rita reads a bunch of old letters, including some following her mastectomy.] Why did I keep all this stuff? Time to let go now.

Sunday January 4, 2009

It is all very hard now. Not knowing if the chemo is working, clearing up the closet in the hall (with E's great help). Wondering if I will make it til spring at least. What to do about Iscador and the lumps it creates. [ED: Rita did not tell Steven about the Iscador and was concerned about the lumps that it caused since they would be obvious when he examined her abdomen, which he usually did. The holistic physician cut back the dose and Rita started injecting her thighs instead of her stomach.] Trying to maintain weight. Not to give up, curl up in bed & let myself die. Very hard all of it. Estate planning. How do I go through this? I loved seeing friends lately. All very hard and painful. My hands are useless. I remember Joan Kelly's words = "Why am I still alive?" and her neuropathy in her hands. Why did I get cancer at 39?

Wednesday January 7, 2009

Yesterday chemo – last session, next week, blood test on Friday.
I have a feeling I need a new dilation.

Tuesday January 13, 2009

I e-mailed Steven who e-mailed Dr. Q and tomorrow I am having dilation in Wellesley. The last few days have been real bad. Coughing all the time. I saw my holistic physician yesterday, keep at low level of Iscador before increasing it. Depressing. I may have to have this dilation every 3 months. If I live that long. There was another storm last Sunday. Estelle starts her new photo class today & is going on Sunday to meet old friends from her Italy days. I will get better. I will get better. [ED: These last two sentences have boxes around them.]

Thursday January 15, 2009

Dilation. No fever. Dr. Q prescribed Prilosec (omeprazole), like what Dr. Barron gave me. Take for 14 days, every 4 months? Will see. Started it yesterday. Still cough, will try swallowing pills today. It looks like berries are bad for reflux, according to the Prilosec webpage.

I spend all my time trying to be alive or “control” my situation. What kind of life is this? Oh, if I could recover somewhat, get a reprieve, go to Argentina....A lot depends on Jan 20.

Tuesday January 20, 2009

Obama’s inauguration. Goose bumps. Incredible feeling. Yes, I can.

Saw Steven. Continue with Doxil, markers came a bit down consistently. We go to Argentina, continue with Iscador, enzymes, Jeanne’s routine. When did I start Iscador? December 10, 2008. Keep better track.

Thursday January 22, 2009

Estelle’s birthday! Last night we bought tickets for Buenos Aires. Today I made an appointment with an estate lawyer and e-mailed my cousin about using his apartment in Buenos Aires. I have goose bumps. A lot to do. This is the right thing. Go with hair!

Thursday January 29, 2009

Yesterday I started with Pantoprazole SOD 40 mg, aka Protonix. It helps, but my head felt funny, like heavy. Try a few days, expensive.

A big cough attack after breakfast.

Friday January 30, 2009

Take pantoprazole first, then protease? No, take protease first with apple sauce. Then the pantoprazole on an empty stomach.

Saturday January 31, 2009

Took pantoprazole first, half hour before breakfast. No protease. Slept more or less well, less cough.

Lots of work on estate and taxes.

Monday February 2, 2009

Chemo at 10:30. I told the oncology nurse about the stiff back.

Wednesday February 4, 2009

Dr. Q said try two pills. I took one last night and one this morning. No difference yet.

My life is not exciting any more. It is an uphill battle every day. Can I do this? Cool down with Estelle, thank God. She is precious.

Thursday February 5, 2009

Reiki session. They are great. Cough continues, maybe it is not the acid that is causing the cough?

Wednesday February 11, 2009

E-mailed Dr. Q that Protonix does not work. My holistic physician gave me another proton inhibitor to try.

I saw a pharmacist/homeopath at Johnson's Drugs this morning, \$75 for a 30' consultation on homeopathic stuff. Gave me two homeos. My trust attorney has started working on the trust. I had a sleepless night!

Thursday February 12, 2009

Yesterday I started the drug that my holistic physician gave me. Prevacid 2x/day. Will see.

Tuesday February 17, 2009

Still trying Prevacid. My hands are useless.

A friend is coming with me to chemo today. Good change.

Saturday February 21, 2009

Estelle is talking about retirement!

Monday February 23, 2009

Started ImmPower, 3 capsules twice a day. Prevacid does not work either.

I need to create a routine/plan for me if I am going to keep living—something to look forward to in my life.

Pleural effusion? GERD? Or both?

February 26, 2009

After Dr. Q at the BI: he and a very nice visiting Irish doctor think it is the pleural effusion causing the cough. I tend to agree. Which means the chemo is not controlling it enough. He gave me a new thing= Zegerid (omeprazole and sodium bicarbonate). What a joke. I am strangely relieved. My first & old metastasis, 30 years ago, 1979.

[ED: Health notes: All the issues can contribute to a dry cough: the cancer (pleural effusion); the lung stent; the esophageal stricture; and the acid reflux. The visiting Irish doctor thinks the cough is caused by the chest (effusion + stent), not the acid. But if that's the case, why does Mylanta help? He thinks the lung is the main cause, but that acid is part of the picture.]

Friday February 27, 2009

Article about estrogen and metastatic breast cancer. I have to try this. Steven referred to this last time we saw him.

Sunday March 1, 2009

Estelle cried about losing me. We are going to Argentina.

I asked Dr. Q to give me Zegerid in powder (the 40mg capsules are too big.)

Wednesday March 4, 2009

What a Day. Like a normal person. Woke up early...[Rita goes on to list her day's activities, including acupuncture, bank, shopping, phone calls.]

Yesterday, a WCCP colleague and I worked 4 hours on the newsletter. She is fabulous.

Friday March 6, 2009

Getting ready for the trip. Ordered a wheelchair and veggie food.

I started the ImmPower a few days ago.

Saturday March 14, 2009

Buenos Aires

Estelle arrived sick with 102F and bronchitis. I am going out.

Monday March 16, 2009

Dinner with [beloved relatives.] I am very disappointed. Not one question about what I am going through. The loneliness of Cancer. Very painful evening.

Tuesday March 17, 2009

I can't wait to be back in Cambridge among people who know & care about me having cancer.

I had a horrific coughing fit. I am stopping the protease and the ImmPower. They make me cough with apple sauce and yogurt.

Saturday March 21, 2009

I have a fever 100.6. Estelle picked it up. I took two aspirin. I have a sore throat.

[ED: We left Buenos Aires on Sunday March 22]

Friday March 27, 2009

I came back with fever, been taking antibiotics. The fever goes up and down. I think I have a cold or the flu because my nose is running. I have to get over this one way or the other.

Saturday March 28, 2009

Temperature is down in the mornings then goes up to 99 or 99.5 in the afternoon. One more day of antibiotics. Estelle has been taking care of me full time.

Today started again with the Zegerid.

Monday March 30, 2009

No fever last 2 days. Marcie had given me an antibiotic=Levaquin 500mg. and a cough thing = promethazine with codeine.

I went for the blood tests and the scan.

[March 31, 2009 Health Notes, appointment with Steven. The 27/29 marker is down. Scan is stable except for a slight increase in pleural fluid. There is not much of it but perhaps it could be drained. Though if the liquid is trapped in the cells, it is hard to drain. A cough after a deep breath could be caused by the fluid. When a lung pushes against something (like the fluid) it pushes back and makes you cough. Regarding estrogen treatment: Rita would be a candidate for it but because of the liver metastases and the fact that the estrogen takes 3 months to have an effect, Steven is not in favor of that approach. And after a while the cancer would come back. He thinks the tumor has mutated because it is affecting the liver now and didn't do that before.]

March 31, 2009. Rita added, in her writing in the Health Notes book:

Afterwards saw Dr. S at interventional radiology who drained 100 cc of fluid but doesn't think it is going to help because air went in [ED: in other words, the lung didn't expand to fill the space]. I disagree. I have to go back tomorrow morning to have a chest X-ray.

Tuesday April 7, 2009

Last night half teaspoon of codeine, coughing at night. Go back to $\frac{3}{4}$ teaspoon. Write to Dr. Q. Some chills.

Friday April 10, 2009

Will do BRAVO procedure April 24. [ED: BRAVO measures acid in the lower esophagus via a capsule glued to the esophagus and an external monitor. The capsule later falls off and is expelled.]

Saturday April 11, 2009

Chills today. Temp was 99.5. Will go to Estelle's house anyway, to see a movie with friends. Working on piece for May 16. [Upcoming conference, Metastatic Breast Cancer Network.]

Thursday April 23, 2009

Pre-Bravo procedures at Beth Israel. I drove myself to the hospital, parked in garage, etc.

Chemo on Tuesday, port was tender, checked for infection. Maybe that is why I had chills?

Saturday April 25, 2009

Yesterday, Bravo procedure. I am still wiped out by the anesthesia and the codeine. The monitor looks like a piece of shit to me. Today it beeped while I was wearing it? What the hell is going on? Estelle is taking care of me.

Wednesday April 29, 2009

It still hurts to eat. Yesterday, chemo and Alvin Ailey. I can't get over Ailey. Revelations is a direct message from a higher power.

I hope I will get some answers from the Bravo.

I am working on getting the checks to pay for the WCCP newsletter. I am tired of my body.

Wednesday May 6, 2009

Stomach rumbling overnight. Coughing quite a bit. Chest still hurts. Did the "capsule" ever come out?

Tuesday May 12, 2009

Chemo today. Less pain when eating.

Wednesday May 13, 2009

Pain is less.

Thursday May 14, 2009

Slept on and on. Acupuncture. Nothing from Dr. Q yet. Got Iscador.

May 23, 2009

No results from Bravo procedure yet. This coming week, last Doxil, for a while.

June 9, 2009

[ED: Health notes: Scan is stable, markers are down. Hormones? Not a good idea. Note: A doctor who Rita heard speak at a conference recommended hormone treatment for metastatic disease. Steven does not agree with him.]

Monday June 30

I am going to speak about the stiff neck and back. X-ray hip.

September 21, 2009

[ED Health notes: The itching on her back relates to chemo. Dismotility (of esophagus) is hard to treat. Regarding the scan: Overall a bit bigger but not much. There are buds of inflammation in the upper lobe of the left lung. A 2mm lung nodule is stable. No adrenal nodules. One liver spot grew from 19 to 27 mm but the liver is not enlarged. OK to take 3 weeks off. Try henna on hands. It binds to raw surfaces and provides a coating. Google henna and hands-foot syndrome.

Friday November 6, 2009

The port was taken out today by an interventional radiologist. Relief. [ED Note: The port was painful and inflamed, looked like a pimple. Assuming infection, Steven recommended heat treatments to bring the pimple to a head. Turns out the port had failed, there was chemo infusion (a bit), and what it needed was no treatment and ice. Hence the removal of the old port and insertion of a new one in a different place. There was a hassle because the surgeon who removed the lump on Rita's side put in the first one and the doc who puts it in is supposed to take it out. But Rita refused to see her again so the interventional radiologist did it.]

Sunday November 15, 2009

Ideas for a really short book are perking up. [ED: I assume she means the book about her cancer story because we talked about that. Given Rita's fatigue and occupation with staying alive, she did not have much time for writing. In fact, her journal had become minimal.

Friday November 20, 2009

Extravasation? Looks horrible. That is what I had on the port, FYI. I think Steven blew it when he had me get another chemo when the port really hurt last time.

December 1-2, 2009

\$\$\$ CVS Money adventure!!! 2 Nexium and I levaquin reimbursed!!! [ED: Rita had been hassling over the coverage of prescription drugs for years. That day was one of her victories.]

December 23, 2009 Last Entry

Yesterday, December 21-22 was the day from hell. I fell twice at home, the second this morning in the kitchen. I lay down on the floor for 30' before I could stand up. When I finally went down to go to chemo, the car would not start. I called a taxi and made it on time. Estelle gave me a ride back & dealt with AAA & downloaded software for the iPod.

Rita's story on the Matastatic Breast Cancer Awareness site: <http://mbcn.org/get-involved/details/my-story-rita-arditti>

Rita Arditti: lived over 30 years with mbc

I am 74 years old and I have lived over 40% of my life with metastatic breast cancer. Yes...for 30 years I have been living with this disease. My cancer story begins at age 39. I was single, living with my 13 year old son, had just started a new job and I found a lump in my breast. This was 1974, just 3 years after President Nixon declared a war on cancer...and information about breast cancer was practically non-existent. People didn't even say the word cancer aloud – it was

whispered. I was the only breast cancer story I knew. I had a mastectomy followed by radiation.

Four years later I developed a persistent cough and I coughed violently for a full year before I heard the words that the cancer had spread to my lung. I relied on my doctorate in biology to help me understand my disease. There was no internet then, so I poured thru books to educate myself. I had my ovaries removed, the cough stopped. It was like a miracle. I was able to be optimistic because my doctor was optimistic... and I had support from a women's cancer group and I was part of a co-counseling community.

In 1983 when I developed difficulty swallowing, it was found that I had an enlarged lymph node in my throat... and I began tamoxifen. I was able to work, have an active life, I ran a couple of races, exercised a lot, looked into all kinds of approaches to treating cancer, and learned about different types of diet. Those were excellent years for me, though of course, every time I went for tests, I worried - a lot. Tamoxifen served me well - for 17 years. It's a long time, I know...but not long enough. Nothing lasts forever - and in the metastatic world that is our biggest fear...knowing the treatment will stop working... wondering what happens next. The fear never goes away.

In 2001, I noticed some changes in my breathing and scans showed a spot on my lung. I was switched to a different hormonal treatment. Then, three years ago, the mets spread to my liver, lung, and bones. I wish there had been more hormonal options available...but it was not so. Chemo, radiation...with the attending side-effects and damage to my esophagus, became the focus of my days. These years have been the hardest. I've been going from one chemo to another, not knowing if they would work, losing much of my sense of taste, losing weight and dealing with overwhelming fatigue... feeling lonely and scared. The last 2 chemos failed me ... BUT... Doxil, so far, appears to be working...and...as a bonus...I'm not losing my hair.

Over the years I have frequently been asked what special medical treatment I've had that's enabled me to live so long with mets... and...I believe I'm lucky that my cancer is not super aggressive...I'm lucky that the cancer has responded so well to hormonal treatments... and I'm so very fortunate to have my oncologist...we've been a team for 30 years. I also believe the unwavering support of both my lifelong partner and my son have been vital to my well-being.

I have a strong will to live and I look forward to better times and less toxic treatments for us all.

Editor's note: [Rita passed away on December 25, 2009.](#)

Rita's op-ed in the Globe, October 27, 2008

FOR ALL the pink ribbons, breast-cancer awareness events, fund-raisers, and celebrations of "survivorship," the facts remain grim. In this country, a woman's lifetime risk of breast cancer is one in eight. In 1975, the risk was about one in 11.

Outside of skin cancer, breast cancer is the most frequently diagnosed cancer in women. It is estimated that in 2008 there will be 250,230 new cases of breast cancer among women. An estimated 41,000 women will die of metastatic breast cancer in 2008. Because we still do not know what the causes of breast cancer are, primary prevention remains an elusive goal while mammography and early detection are the focus of attention.

Since World War II, the proliferation of synthetic chemicals has gone hand-in-hand with the increased incidence of breast cancer. About 80,000 synthetic chemicals are used today in the United States, and their number increases by about 1,000 each year. Only about 7 percent of them have been screened for their health effects. These chemicals can persist in the environment and accumulate in our bodies. According to a recent review by the Silent Spring Institute in Newton, 216 chemicals and radiation sources cause breast cancer in animals.

Nearly all of the chemicals cause mutations, and most cause tumors in multiple organs and animal species, findings that are generally believed to indicate they likely cause cancer in humans. Yet few have been closely studied by regulatory bodies. There is concern about benzene, which is in gasoline; polycyclic aromatic hydrocarbons, which are in air pollution from vehicle exhaust, tobacco smoke, and charred foods; ethylene oxide, which is widely used in medical settings; and methylene chloride, a common solvent in paint strippers and glues.

There is also broad agreement that exposure over time to natural estrogens in the body increases the risk of breast cancer, so it is important to consider the role of synthetic estrogens in breast cancer development. Many other chemicals, especially endocrine-disrupting compounds - chemicals that affect hormones, such as the ubiquitous bisphenol A, which is found in plastic bottles and cans - are also thought to raise breast cancer risk. Endocrine-disrupting compounds are present in many pesticides, fuels, plastics, air pollution, detergents, industrial solvents, tobacco smoke, prescription drugs, food additives, metals, and personal-care products including sunscreens.

Is there definitive evidence that these substances cause breast cancer? Have they been sufficiently studied? Well, no. We need to know more about the timing, duration, and patterns of exposure, which may be as important as dosage. But shouldn't we do everything possible to reduce exposure to the suspected chemicals? Shouldn't we take precautionary measures, as we continue and

deepen the research? In Massachusetts, the leading cause of death in 2006 was cancer. It is time for action.

In our state, the Alliance for a Healthy Tomorrow, a coalition of more than 160 organizations, has worked for the passage of the Safer Alternatives Bill, which would create a program to replace toxic chemicals with safer alternatives when feasible. The bill would establish a pragmatic, gradual approach to reducing health impacts from many of the toxic chemicals that we are exposed to in everyday life. The bill passed the Senate unanimously this year, but was not voted on by the House. The alliance will introduce it again in the 2009 legislative session.

Yes, we need early detection but also primary prevention, and, of course, effective treatments for those of us with extended disease. Rachel Carson, who herself died of breast cancer in 1964, said it best: "For those in whom [cancer] is already a hidden or a visible presence, efforts to find cures must of course continue. But for those not yet touched by the disease and certainly for the generations as yet unborn, prevention is the imperative need."

Rita Arditti is one of the founders of the Cambridge-based Women's Community Cancer Project, a grassroots organization committed to cancer prevention. She has been living with metastatic breast cancer since 1979.

Credit: Rita Arditti. Boston Globe

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April 15, 2008

Hi, Estelle: dr. Y called me this morning and said that unfortunately there were cancer cells, consistent with breast cancer, estrogen and progesterone positive. She called also about taking out my stitches and I said I wanted to wait a few days till it is less raw. She said she called [the oncologist substituting for Steven] but she was not there and left her the message and suggested if I go see her later this week or next week I call Dr. Y's office and she or somebody else will take the stitches. Nice woman.

Well, obviously I was right in my hunch about this thing and will need to talk with [the oncologists] about this. Shit, one more thing to deal with.

But with your support, I feel I will make it through this one too.

tons of love,

Rita

Things to append/link to
Anticancer review (ask Cambridge Naturals?)

Mary Kirk's review of my book in *The Feminist Teacher*, Vol 18, #2, 2008!