





EXCERPTS FROM

Julie's Journal

BY JULIE TROCCHIO, M.S.

I sat in a doctor's office while the urologist calmly and rationally drew me a picture on exam-table paper of where the cancer was and what we would do about it. I sat calmly listening to him, but I definitely was not rational. I could not think straight.

What he didn't know was that in those few minutes of our conversation, I had been transformed — from a busy, healthy person to a cancer patient who was about to step into the unknown and perhaps closer to the end of the line. He has no idea what is really going on inside of me, I thought, so how can he take care of me?

When our visit ended he said, "Well, by our age, we all get something. This is yours. Me, I have a bad back."

But cancer is different. So is every serious illness. Walking back from that visit, I decided I would try to use my experience to show doctors and others what it was like to have cancer and to be a patient. I started by trying to describe how cancer shakes one's sense of self, and that became the first entry in this journal.

CANCER MADE ME LOSE MY COOL

One thing cancer taught me is that robust health can be deceiving.

I have always thought of myself as fairly cool. I am an active, walking-everywhere, traveling-to-interesting-places, non- (well, almost) TV-watching lady. Then I heard I had cancer — probably treatable, and even better, curable. And now I am none of those other things. I cannot exercise except for some stretches and short walks; my trips are cancelled; all my conversations seem to be about my health or lack of it. Oh, and I watch "Storage Wars" on cable TV, over and over.

I have so much time on my hands that I am boring myself. Even my dogs are finding me less interesting, missing their long walks.

I miss laughing.

I used to talk to gym friends about politics, art and going to the ballet. Now I talk to my doctor about going to the bathroom. When he asks, "How are you feeling?" how do I tell him, "Uncool," and have him realize this is serious?

YOUTH

They are so young, the doctors doing a residency in this specialty. "Where did you go to medical school?" I ask, and I learn they went to Harvard, or Georgetown, or George Washington University, or other satisfactory places. "Well, that's good," I say, while thinking, "Who was president when you were born?" Oh, dear.

My friend said I should ask how the bars were around their schools. If they say, "I was too busy

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studying to find out,” it is good news. I ask this once to a young resident, he replied, and then I tell him why I asked. “You got me,” he said. The bars in LA, he had answered, were just fine.

“No one wants to have an urologist,” I observe to one of the residents. “Most of us want to have a family doctor, lots of us want an obstetrician, a few want a plastic surgeon, but no one wants a urologist, you should know this.”

“But if we need one, we are very glad you are there,” I quickly tell him. “We are glad to hear that this is a special specialty, for the best and brightest.”

COVERING BASES

I went to confession. I had not gone since before Vatican II, so the timing seemed right. The priest, Father O., new to our parish and wonderful, said God forgives us our sins, but the sacrament of reconciliation celebrates grace and forgiveness. Father O. said he goes twice a year, sins or no.

My penance was an “Our Father,” and he asked if I remembered the Act of Contrition. I did, but

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it evolved into the *Memorarae*, “despise not my petition but in thy mercy hear and answer me,” which I have been saying at every stop light.

A lot of nuns are praying for me. According to Jennie, one of my two daughters, her college roommate has all of New Jersey praying for me. My primary care physician is praying for the cells to reverse themselves, and she is a very good prayer. A nun from Syracuse is up for sainthood and needs a miracle to make it all the way, so I have been praying to her. I think I have my bases covered.

THREE CHANCES

In religious circles there is a joke about a man about to drown in a flood. A car comes by, offering to take him to dry land, but he says, “God will provide.” The waters rise to the second floor of his house and a boat comes by, offering to take him to safety. “No,” he says. Then, when the water gets

so high he is on his roof, a helicopter tries to save him, but he insists that God will provide. When he drowns and gets to heaven, he asks God why he did not save him, and God says, “I sent a car, a boat and a helicopter.”

I, too, had three chances. When I first saw blood, and going to the bathroom hurt, my doctor said to go to the ER and let’s see if it is an infection, the most common cause. The physician assistant at the hospital gave me a prescription for an antibiotic and said, “See a urologist.” But I got better with the antibiotic, so I followed up with my doctor because a urologist was bound to do something awful to me, and it was probably just an infection.

I looked up “blood in the urine” on the Internet and read, “*This must be attended to.*”

At a sodality meeting, Betty said, “*I saw a drop a blood, just a drop, found out it was kidney cancer, had surgery and now I am fine.*”

Three warnings.

I kept treating myself with lots of fluids and asking my physician, often when I was traveling, for a prescription for urinary tract infections. When I mentioned the blood during a physical, I made light of it, slipping it between “I have been eating more vegetables,” and “I think my eyes are getting worse with age.”

I told my GYN that when I got a urinary tract infection, I saw blood, and sometimes after spin class. “At your age, that happens,” she said. “Don’t stop spinning, it is great exercise.”

When I told my boss, a nurse, she asked, “How long have you been treating this as an infection?” When I said two years, she said, “*Oh dear.*”

I am a nurse too, or at least used to be. I should have warned myself.

HOW I FOUND OUT

I thought I was having lots of urinary tract infections, until we did a culture and no germs were there.

I saw a urologist who said my symptoms were most likely from stress, so I should take a vacation and drink less coffee, but to get a sonogram and “give us a sample to be on the safe side.”

The sonogram showed something was there.

“These tumors are very common,” said the radiologist who looked at the sonogram. “Take it



out, get checked every few months for a few years, and you are good to go.”

But there were cancer cells in the sample.

“Get a CAT scan, and schedule surgery to get it out,” said the urologist. “All tumors have some cancer cells, so it could be minimal, but let’s find out.”

I waited two weeks to hear cancer was in the lining of the bladder but not the muscle.

“It could be hiding. I am haunted by the faces of patients who had hiding cells, so let’s dig deeper and biopsy again,” said the urologist.

“OK,” said I, who used to be afraid of anything a urologist might do.

Let’s do it and wait some more.

WHY, HOW?

So how did I get this cancer? I don’t smoke, at least not since everyone did. I don’t drink diet drinks or eat processed foods. I exercise and have a positive outlook on life. I think it is those X-ray machines in airports. I told this theory to my recovery room nurse, who said I shouldn’t blame it on airports. He asked: “Were you ever exposed to well water? It might have had arsenic.”

Now the research is telling us that smoking — ever — seems to be responsible for a lot of bladder cancer. So, maybe, because of bad decisions in my 20s, this was my fault after all.

NORMAL

Between procedures, I went on a short business trip and loved every minute: driving to the airport, getting a newspaper, standing in line to board, finding a nice restaurant. At my meeting, no one looked at me with sad eyes or had any idea of what was going on in my bladder. “How was your trip?” asked daughter Elizabeth. “Wonderful,” I replied, “I felt so normal.”

“Well, you are normal,” she said.

“I sometimes don’t feel normal when I think of what is going on,” I said.

She looked at me and said, “Then don’t think about it!”

So I stopped thinking about it most of the time, and she is right. It helps me feel normal.

COOKIES

I make my doctors cookies. I want them to know

that I am not just the 2:15 appointment, but *someone*. I want them to know I appreciate their gifts but that I have gifts, too, even if it is just mix-

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ing butter with sugar and flour and putting it in the oven. I want them to look forward to seeing me and what I bring, to give me full attention. It always worked for subcontractors when we had our house remodeled. I am hoping it works on doctors, too.

WHAT PATIENTS WANT TO KNOW

The cancer center websites tell me a lot: the warning signs, probable causes, cell structure, treatments, percentages. But the National Institutes of Health (NIH), the Cleveland Clinic, Johns Hopkins, Sloan-Kettering, Dana-Farber — they don’t tell me what I really want to know: What will happen next? Will it hurt? Will it work? What then?

HARD LESSONS

My friend Lawrice said I should ask, *What am I supposed to be learning from this?*

So, OK, what have I learned: I have more friends than I thought and they are better friends than I thought. You cannot do enough sit-ups to protect yourself from cancer. Feeling well does not mean being well.

I wonder if this is what she meant?

REFERRALS

“I am really a lifestyle urologist,” says my doctor (something I wish he had told me before operating on me twice), “so I am sending you to two specialists.”

One is an oncologist who specializes in blood and urinary cancer. I am a bit concerned about this because those cancers don’t seem to have much in common, but she did a fellowship at NIH so that is all right.

The other referral is to a urologist who specializes in cancer. I am concerned that is a euphemism

for cancer surgeon (which it was), and surgery is not my personal treatment preference. But he was kind and competent. Just what I needed.

A classmate's husband is a cancer guru and promised to look over my treatment plan. A friend came through with the name of a personal trainer who has recovered from cancer and helps others to do the same. The Cancer Hope Network gave me Zoey and Anne, lovely ladies who have been there, done that, with bladder cancer. I am assembling quite a team.

ONCOLOGY

As a student nurse, a real nurse, as a visitor, I have passed many doors labeled "Oncology" and each time, yes, *each time*, I have said, "Not me, thank God, this is not for me." Today it was for me, and I was happy to get the appointment so quickly. The office had dim lights, soft music and there was a waterfall. The oncologist was warm and welcoming and sympathetic. But still it all meant CANCER.

So it is not an infection, not stress, not a benign tumor and not an easy kind of cancer. It is the bad kind of bladder cancer (who knew there was a good kind?). Three doctors explained it to me, and I think I finally get it, although I acted like I did the first time. I say, "Take it out, get rid of it, I hate this troublesome bladder."

But then I think, *maybe if I pray hard enough, a miracle will happen and it will go away by itself*. But no, that won't happen. I need to be optimistic that surgery will go well, and I will soon be better.

So there you have it, all the stages: denial, anger, bargaining and finally acceptance. Guess the books are right.

TRISH

Trish was in my nursing school class and now does mind/body work. On the phone, she asks, "What is troubling you right now?" I say, "I think of surgery as an assault on my body, a violent act about to happen."

For 30 minutes, she guided me to realize surgery will be healing, not damaging. "You must talk to your body," she said. "Tell your circulatory system to get ready, your immune system to stay strong. Tell your urinary system you are sorry it is hurting. Tell them all you will need them to get well, that you love them and that you will all get through this. This works," she says. And I believe her.

GETTING READY

Finish this, finish that. Cancel this meeting, reschedule another. Find a substitute, find a gift to thank substitute. Tell her, her and him. Buy lightweight books and lightweight robes. Change dental appointment. Make list for wonderful sister, Suzy, who will be coming from Wisconsin. Google "gas pains after abdominal surgery," and buy what is recommended. Get pre-op prep and post-op pain meds. Buy and send birthday presents, order Christmas presents. Pack a bag, repack. Go to church to get blessed. Rest. Reassure everyone. Thank people for praying.

Bladder cancer has become a full-time job.

GOALS

Here are my goals for surgery:

- Don't get an infection
- Stand and walk that night
- Walk a lot
- Get my digestive system working quickly so I can get home
- Leave cancer behind

THE HOSPITAL

Here are my observations:

I always thought that ICU nurses cared for machines, not people, but turns out they are the best, most compassionate nurses in the world. I had the same thoughts about operating room nurses, and the best nurse I met was an OR supervisor. She took charge of making sure I did not have pain after surgery. Some things you have to experience to believe.

All the quality policies in the world cannot make a quality hospital. Nurses had policies for doing a nursing assessment on each 12-hour shift, but only one nurse did so. All staff must wash hands entering a room, but only 1 in 3 did. When I asked a nurse to wash her hands, she gave me some look!

Travel and temporary nurses should be banned. They did not know the equipment or the policies. Nurses and aides who worked there the longest were the nicest, most caring, most competent. Longevity matters.

A teaching hospital is full of teaching. My first morning walking, I opened my door to the sight of about a dozen green-clad med students in short white jackets, spilling over the chairs in the chart room like puppies. I thought I was in an episode of "Gray's Anatomy."



The residents are so earnest, even when I tried to coax personal information and gossip. One of them, the most solemn, said very matter-of-factly when I had a discouraging moment, “Hey, this is the biggest surgery we do, and you are doing great.” It was the best hug I could have had.

Doctors don’t talk to nurses. These groups are on parallel paths, caring for the same patient. I would say to a resident, “... as I told the nurse, this is happening,” and it would always be news. They work in teams, but doctors and nurses are not on the same team. Makes me wonder what team I am on.

Infections happen, despite all efforts. Five days after discharge, I was in the emergency room for 10 hours, then readmitted to get IV antibiotics.

RECOVERY

It takes a village to recover from surgery. Every day in the hospital, I was visited by the residents on my service and a team of pain specialists. My daughter Elizabeth came daily, usually in the evening to play a few hands of gin to help me fall asleep. My wonderful sister Suzy came to take me home, and she never stopped cooking and doing. Her custard was amazing.

Daughter Jennie left her Florida school where she teaches — and her dissertation — to spend a week, ordering clothes and supplies and taking

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me on walks outside. Home-care nurse won’t quit until I get the hang of self care. Husband stepped up to all the chores. I told friends we did not need meals, but several brought soup, and each bowl was wonderful. I am not used to needing people, but needing I did, and the help was not only welcome and humbling, but healing.

WORDS TO LIVE BY

So many lovely and funny and touching cards and notes have come. But my favorite words came from a catalog: “Life is not about how fast you can run or how high you climb, but how well you BOUNCE.”

THE PORT

I am back in surgical admitting for the fourth time; I am getting a port for easier chemotherapy. I see some familiar faces, including the lovely lady who, my first day, had just graduated from probation to full time and who had taken down my information each time. (Actually she collected the exact same information each time — *what are electronic records for?*)

Everyone is nice, as always; everyone knows what they are doing; everyone went to good schools (I always ask, and I quiz the radiologist on bars in my hospital’s neighborhood). As I am wheeled into the room, my nurse and I spot a dozen blue-suited young men and women.

“FBI?” I ask the nurse. “No, looks like Secret Service,” he replies. Turns out they are med students interviewing for residencies in radiology. “Good luck,” I say to them.

I had been promised music during the procedure and that it wouldn’t hurt a bit. The music is Bing Crosby Christmas carols, and I tell the radiologist a surgeon would not stand for this. But they were right about it not hurting.

PREPARING FOR CHEMO

Monday is my first day. Daughter Elizabeth is coming with me, and we will be bringing catalogs and an iPad for shopping, because it is “Cyber Monday.” We have done other things to get ready; for example we packed snacks and books and hard candies from sister Suzy, who heard that chemotherapy can leave a bad taste. Elizabeth’s friend, Richard, who is an oncology nurse, gave me *Chemotherapy for Dummies*, which I have read carefully. I am wearing Betty’s *Cancer Survivor* bracelet because she is cured and does not need it, and Jennie’s *Fighting Bladder Cancer* bracelet which has the official bladder cancer colors: marigold, blue and purple. I have asked my sodality to pray that the chemotherapy will be healing, not hurting.

Yesterday we stopped by church to get a blessing for this next stage of the process. Father O. proved to be a powerful advocate with the Almighty before my surgery, so I am sticking with him, and I thanked him with blueberry cookies.

I have been listening to and will bring an imagery/visioning/meditation tape. I decided against

the ones with warring themes — little soldiers or motorcycle gangs battling cancer cells — in favor of a tape about a glowing light and being surrounded by loving people from my past and present.

I changed my toothbrush, as you should for any big occasion. I also had my hair done. Looking my best for a new audience seemed the right thing to do.

Yes, I am ready.

ROUND ONE, DAY ONE

Waiting seems to be the permanent speed in oncology. Everyone is gentle, and no one is in a hurry. Good thing I left my type A personality behind months ago. We wait for blood work, then to see the resident, then to see my oncologist, Dr. A-C.

Blood work shows red cells up, so I can cut back on the iron pills. I am able to advise the resident what to do for her twin boys who are teething. Dr. A-C is informative and caring, and I am glad Elizabeth can meet her. Elizabeth says, “I feel well-informed now.” The doctor writes me a prescription for an anti-nausea drug that she says I will not need.

Once in the infusion room, sunny and surprisingly cheerful, my chemo nurse explains everything and gives me hand-out information about the drugs and side effects.

“Psst,” says Shirley, my neighbor to the right, “I have found it best not to read those things. They only put ideas in your head.” So I put it all away and start a great mystery novel.

Elizabeth stays for five hours, and we eat our way through the treatment: graham crackers, nuts, turkey sandwiches, soup. We have so much fun talking that we forget to cyber-shop. When it’s time for Elizabeth to get ready for her job, Debbie from my office comes to sit with me, and she swears it is not bringing up past bad memories of her own chemotherapy (which she did without taking a day off). My neighbor to the left shops feverishly on his computer. “Yes!” he yells, “I just got a \$185, complete Nerf war game for \$56!”

The drugs start. First I get saline for hydration, then two anti-nausea medicines and a steroid to boost everything, then Drug No. 1 and then No. 2. For each of these big-boy drugs, I listen to my imagery tape and have a vision of being surrounded by friends and family in Cape Cod with a

warm light coming from a fountain that flows into every organ, every cell.

I did not know how I would feel: weak, sick? I had told myself, *I will feel exactly the same*. But what I feel is good. It’s working — all of it, the therapy, imaging, the prayers, the support (I got over a dozen “You go, girl” e-messages during the day), and the belief that all will be well.

SIDE EFFECTS

There is nothing humorous about chemotherapy’s side effects, but there are some heartwarming signs: Elizabeth brings home a thermometer and saltines. Wonderful sister Suzy researches integrative care solutions and suggests “sea bands” used for sea sickness. Jennie orders them — and everything else Amazon has for nausea. Husband shops for oyster crackers and ginger ale. Lawrice brings chicken soup and good company.

Wonderful brother Peter sends the most unexpected thing: ice cream. I think mint chocolate

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chip may be chemotherapy’s equivalent of penicillin for strep. Jill, who has had chemo twice, promises to walk me through this, and she promises it will not feel like this every day.

My insurer had a nurse manager call; she mostly talked about herself but distracted me for 15 minutes. And the dogs won’t leave my side, but that might have to do with the oyster crackers I generously hand around to all of us.

CHEMO CULTURE

My college roommate, Margaret, takes me for my second chemotherapy. She is a labor and delivery nurse; I knew she would be helpful. She gets a phone call right when we reach the treatment room. “Is it OK to use a cell phone here?” she asks the infusion nurse. “Of course,” is the answer. “There are no rules.”

In other words, what happens in oncology, stays in oncology. It’s true. Where in other parts of the department doctors rule, here, (fabulous) nurses rule. An example: Meg, my nurse, hears that I have been feeling like crawling in a hole, and



she asks to see what I have been prescribed. She rearranges the order and times of the medicines and says, "I think this will work for you."

There is a friendliness here you never see on the Metro or at the grocery store. "Your purse is great," I tell the wife of a chemo neighbor. "\$75 Vera Christmas item, my sister got it at an estate sale for \$1!" she replies, and we spend 20 happy minutes talking about bargains and how to find them. "Love your dress," calls a lady who is leaving for the day. "Vermont Country Store," I shout across the room. "They mostly sell candy and nightgowns, but they have three dresses, and I got all three!"

Around the room, lots of pens and papers come out, since everyone here is looking for advice, any advice.

SHOES AND GOING PLACES

I go into my closet for a bathrobe and look down. Rows of shoes: four pairs of work shoes, workout shoes, casual going-out shoes, fancy-event shoes. They all seem part of a different life, a different me. I used to go to work, to the gym, to church, to Starbucks, to parties. I don't go to any of these places any more. I go to the hospital, to oncology, to the mailbox at the end of the block to post thank-you notes, and to bed. *When this is over, where will I go? To the old places? Will I get my old life back?*

BREAKFAST

Last night I decided that when I get up, I, like a normal person, will take a shower. Now, this is a bigger deal than it sounds. It will be my first post-surgery shower, and it involves covering key post-surgery parts of me with Saran Wrap. I will look like the housewife in "Fried Green Tomatoes" who is trying to add spice to her marriage.

But when I wake up, a shower is not on the agenda. I don't feel well. I go to the refrigerator and pull out the first thing that looks good: strawberry ice cream. *No*, I say to myself, along with another mouthful of fruit and cream and sugar, *you are nowhere near normal*. Then my daughter gets up and plops on the couch with her breakfast before heading for work. She is eating butter pecan ice cream. She is as normal as American pie, and so, for a while — as I am eating my second helping — I feel as normal as can be.

VISITORS

A came a week after surgery and stayed too long. B came for 15 minutes; just right. C came with

caramels which took out a filling. D came with a movie and said, "Don't talk, let's just watch"; it was grand. E, a health policy specialist, came wanting to know all the details about what the hospital did right and wrong; I loved it. F, G, H, and I dropped off soup, cookies and plants but did not come in. Are they afraid of what they might see? Or maybe they feel a cold coming on. J came but never mentioned anything to do with my illness. K and L came and took me to chemo; bless them. M and N said they were coming but never did. O and P said they would come but had colds; thank you! I told Q I had cancer and she came over that afternoon with a vanilla cupcake. R said to say when I was feeling well and she would come for a short visit and bring lunch.

I love you all.

A TRIP TO NORMAL

Round One, Week Three, no chemotherapy. I started feeling good last Friday and it has continued: energy, appetite, engaged. I bought a few last Christmas presents, wrapped everything and sent out cards, I visited with friends and made dinner for Elizabeth and her friend when they bought the tree. I answered some work calls and wrote a Power Point presentation I may or may not do in January. I took a shower without Saran Wrap (yes, it was a very big deal) and had my hair done. Talked to a friend who had knee replacement surgery and realized some people really have it tougher than I do.

ROUND TWO, DAY ONE

Beth, from my sodality, takes the day off from her consulting-firm job to take me to chemotherapy. She brings books and card games. "There is a lot of up and down to this, isn't there?" she observes, as I get up for a blood test, then for height and weight (*Does chemotherapy make you shorter?* I wonder each time they tell me to stand up straight), then to see the doctor, then to go to the sunny infusion room.

My first neighbor is a middle-aged African American who is fast asleep and gently snoring. A half hour later, she is done. "Time to go to work," she tells me. More power to her. I plan to watch "Elf" when I am done.

Before we know it, all four of my drugs are in, I have won four card games and we are on our way home. I napped and fell asleep as just as the North Pole whale waved good bye to Elf and said, "I hope you find your dad."

Because it was Christmas Eve, I went home with hope in my heart and took my medicine.

WHAT LIES AHEAD

When I see the doctor, I am ready, for the first time, to ask about the future. “You told me my type of cancer is aggressive and so rare there have not been many studies. Has there been anything new?” I ask. She explains that this cancer is a subtype of a common cancer and that the path we have chosen, surgery and chemotherapy, is clearly correct. “Will it be ... effective?” she finishes. “Yes, I think so.”

“Then,” I ask, “will we take the port out when we are done?”

“Well, sometime we keep it in for a while,” she says. “If cancer recurs, it is likely to be in two or three years. So if it doesn’t bother you, we might keep it in. So yes, this will work, but we are keeping options open.”

MORE ROUND TWO

I knew it could be more intense, but I also knew I was well-equipped with drugs and gadgets and prayers and good will. But it was awful.

Every day I would say, tomorrow will be better, but it was not, and by the end of the week I was retching. I despaired. Drugs would let me sleep for a while, but that was all they seemed to do.

Daughters Jennie and Elizabeth took me to treatment, and wonderful Meg, infusion nurse, said we can do something about this. She asked the doctor on the floor, surely one of Santa’s finest helpers, and he prescribed a cocktail of three drugs to take over five days, before meals (*what meals?*) and every three hours. “You will feel better soon,” said Meg.

Because it was Christmas Eve, I went home with hope in my heart and took my medicine. I woke up at 5 a.m. after a good sleep, feeling *almost good*. I went back to bed to cuddle with dog Callie, and we both nibbled saltines.

Now I am ready to make Christmas — or at least to supervise.

A GOOD DAY

It is my week off from treatment. What a gift! By Wednesday, I am feeling good most of the time, and on Thursday, I am a real person: take a shower; exercise; sort clothes and bring a big stack to the

thrift shop; work for a couple of hours to plan the weeks and months ahead; made soup; and talk to many friends on the phone. Days like today make me realize there really is the tomorrow of “Annie,” a day where the sun comes up, come what may.

GETTING READY FOR ROUND THREE

I am bracing myself, but I am also prepared. College roommate Margaret, bless her, is confirmed to take me for my treatment, and I am looking forward to spending time with her. This has been the cancer dividend — time I never would have had with people I love. I visit with Father O. who tells me not to get too much inside myself, which I think means not to feel sorry for myself, of which I plead guilty. He reminds me that God loves me.

I make an appointment for acupuncture for the day after my treatment. My friend Judy, who is having a “brush with colon cancer,” highly recommends Dr. Hu and her treatment.

I have all my medicines in a bag — those that have worked and those that have not. The fridge has diet soda, the cupboard has saltines, I have Suzy’s sea bands and Jennie’s Amazon mints. I guess this is what happens when a type A lady gets cancer. She tries to control as much as she can — or at least go through the motions. Round Three, here I come.

ROUND THREE

Margaret picks me up, and we make great time: drive through the city, check in, blood work, the doctor, into infusion. We learn that Dr. A-C has divided my dose of what I call the big-boy drug between today and next week. This will be my final round, because the last round indicated some possible kidney damage. As relieved as I am, I also ask outright: “What do you think will be the course of my cancer?” and the wonderful oncology fellow says, “There is a very good chance the cancer will not recur. It is true that if you did not have the aggressive variant, your chances would be better, but I still think there is a good chance.”

Boy, I needed that, because I was starting not to believe. At infusion I meet the doctor who wrote my Christmas Eve orders. “You gave me Christmas,” I tell him.

ACUPUNCTURE

It turns out that Dr. Hu is a cancer specialist. In China, she tells me, to be a doctor one must study Western medicine, herbs and acupuncture. She is no-nonsense but very gentle. She takes a short his-



tory, asking good questions, and tells me yes, she can help with chemo symptoms — but what she really does is improve the immune system to protect against cancer. She says she has had patients expected to live less than a year whom she has continued to see for more than five. Johns Hopkins University Hospital oncologists refer to her, and her partner is an MD affiliated with George Washington University Hospital. I think I am in good hands.

Nothing hurts, but the treatment is a bit uncomfortable. I have to lie still for 25 minutes which is hard to do, but I say the rosary on my fingers and by the time I am at the fourth decade, I'm done.

Nothing dramatic seems to have happened, but I do not need any drugs for symptoms until Saturday — when I hit the wall. That day I have another acupuncture treatment and am much better on Sunday. I don't understand it, but I have faith, which in this case might be the more important.

THE LAST TREATMENT

From my mouth to God's ears. Yes, the last treatment: second half of the big-boy drug, and all of his little brother. Daughter Elizabeth is here with cards and to watch “Breakfast at Tiffany's.” The doctor confirms this will be the last chemo treatment, but I am to come back Wednesday for blood work and more fluids. The nurse did not like the look of my port, and after conferring with Dr. A-C, says, “Get it looked at, ASAP.” This, it turns out to mean, is tomorrow at 7 a.m., and probably involves a couple of little stitches.

THE PORT IS GONE

I get to Admitting at 7 a.m., but my paperwork does not. Make another appointment, they say. Or we can look at it in a few hours and make another appointment to fix it, they say.

But, remembering the nurse's ASAP admonition, I say I am sure they can straighten it out.

“But we never got your paperwork!”

I stand fast. I get seen. “Wow,” says the physician assistant, looking at the port. She asks if she can show others. “Wow,” says each of the three young nurses she calls over to inspect the port.

I tell her my last treatment was yesterday, and she says, “Good. This should come out.” I tell her my oncologist suggested keeping it in a few years, just in case, but the physician assistant waves that off: “Then get a new one if you need it.”

This is not an unwelcome development. The port was a bit uncomfortable, especially when I was trying to sleep, it was a potential source of infection and it would be a constant cancer reminder, as if I needed one. So out it comes, as easy as it went in but with no blue-blazered residency applicants or Christmas music. The so-called light sedation makes me sleep like a baby.

Once I'm home, a neighbor stops by with an orchid, and a sodality sister comes with a basket of goodies. “You look great,” they both say.

Not bad for a cancer patient who has just had surgery.

NOT DONE YET

I go for blood work, the white blood cell booster and hydration. The charge nurse says, “I believe you have bought yourself a transfusion.”

My blood count shows very low red blood cells and hematocrit. But I don't want a transfusion, and I have talked my way out of it before.

“How about having my doctor look at me?” I ask. (That works; last time, the doctor said I didn't

Nothing dramatic seems to have happened, but I do not need any drugs for symptoms until Saturday — when I hit the wall.

really need the transfusion because I looked OK. This time I happen to have some lipstick and blush with me, so I know I can pull it off.)

“We will certainly check with your doctor, but numbers don't lie,” says the nurse. *Game over.* Later that day, a tired, anemic me is reporting to Hospital Admitting for blood type and cross match. As the tech approached for the blood draw, I say, “This is my fifth stick of the day, and I am giving a prize for whoever does it best.”

She straightens up, gets herself in game mode and begins. I have to stop her to confess: “I'm sorry, there really is not a prize, but I might have some pretzels in my bag.” (Still, she was the best.)

I have to report back the next day, and I am very nervous about getting a transfusion. The hardest part was the hour in admitting (oh, the paperwork!). But getting two units of blood was a snap. The nurses were great, and I had no reaction. (A friend asked if I could tell if I have ballerina or accountant blood in me now.)

ASHES AND VALENTINE'S DAY

A month later, on Ash Wednesday, while getting ready for a CAT scan, I hear an NPR reporter say that St. Paul's Episcopal Church is giving out ashes at the Foggy Bottom Metro stop, right next to my hospital. Before I sign in for the scan, I go outside and approach a beautiful woman wearing a clerical collar (a bishop, I find out later!).

"I am having medical tests this morning and would like your blessing," I tell her. She gives me a cross of ashes and reminds me I came from the soil and will return to it. Then she wishes me well with the test.

The next day was Valentine's Day. Back in November, daughter Jennie and I designated this day as Victory Day: I would be through chemotherapy, and she would have most of her dissertation under her belt. We both got through December and January looking forward to this day, and we rejoiced when the stores started featuring Valentine decorations.

When February 14 arrived, I was back at work and she had committee approval of her first three dissertation chapters. She sent me a plaque that reads: *Life is not about how fast you can run or how high you climb, but how well you BOUNCE.*

GOOD RESULTS, THANK GOD

My wonderful oncologist gives me the news: the CAT scan showed no sign of disease, and she will see me again in three months. Thanks be to God and to Mary and the other saints I prayed to, and thanks to everyone who prayed for me, especially my CHA and sodality families.

Thanks to my real family, my daughters who cheered me well, my husband who worried me well, sister Suzy who walked each step of the journey with me, and brother Peter who kept me in ice cream and news of the real world.

Thanks to neighbors and friends who brought nourishing soup, mindless novels and good conversation. Thanks to almost all the doctors and nurses. Thanks to those who stayed with me dur-

ing treatments. Thanks to NPR for keeping me company and keeping me informed. Thanks to my team and my village. It might not be forever, but for now, you made me well.

END NOTE

I have spent a good part of my life involved in health policy, and before that, clinical nursing, but being a patient was unknown territory. There is much I never knew. Could I teach others — and would it help? My cancer journal could and should be a learning experience, for me, for caregivers, for others. A few entries I wrote to show doctors that often they do not listen or pay attention. Some entries I wrote to send to long-distance friends and families to tell them what was going on, that not only was I doing OK, but that I was finding humor in unexpected places. From the hospital, I wrote that it is one thing to say "this is the rule or the way we do things" and quite another in practice. I wanted to show other cancer patients, "You can do this; I did."

Some entries I wrote to tell people not to be afraid to visit persons with a serious diagnosis, because we are still us, only maybe a bit nauseous and probably overly self-centered. These are all reasons why I wrote this journal, and why I welcomed the invitation to tell this story in *Health Progress*.

I am back to work, back to the gym and back to my life. My first day back at the office, all — except for the fresh flowers from the staff — was the same, including my calendar. The calendar still said October. My first thought was that I had lost four months. But then I realized they were not lost at all. They have been a time of learning and teaching, of friendship and grace. I hope my cancer journey is over, but if I get sent along another leg of that trip, I will be ready and less afraid.

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