

CHEMO ROUND ONE

I was so glad that Tom and my sister Cathy had come to Vermont to be with me for my first round of chemo. The day before it began, I was summoned to the hospital for “chemo class,” an introduction to the treatment. My nurse, Kristen, had a trainee with her, a nurse who would be learning the ropes for teaching the Introduction to Chemotherapy class in the future. Since my sister had gotten to town a few days earlier, I dragged her with me.

Sitting in one of those faux-cheery consulting rooms, Kristen started to explain the technical aspects of the chemo. She described the precise drugs that I would be receiving: Rituximab, Doxorubicin, Vincristine and Cyclophosphamide, Prednisone, on and on the list went, until she mentioned an anti-emetic called Ondansetron.

As Coopers, my sister and I have both been well-trained to find something funny in almost every life situation. Sometimes it’s a shield, and sometimes it’s simply for our own amusement. So when we heard the word “Ondansetron,” Cathy and I, in the same breath, got the giggles. It reminded me of the Christmas poem, and I turned to her and whispered, “On Dancetron! On Dashetron! On Donner and Blitzatron!” She, meanwhile, thought “Danc-e-tron” sounded like a dance move, and started humming something back to me that sounded alarmingly like the BeeGees from *Saturday Night Fever*.

Kristen finally had to stop talking, because Cathy and I were gasping for breath, tears flowing down our faces, our giggles having turned to full-body gales of laughter. The trainee nurse watched, worriedly, as Kristen whispered to her, “This is. . . um. . . pretty unusual. As a rule, they just sit there quietly. . .” It looked like the trainee wanted to call for a psych consult. Cathy and I, however, were snorting and trying to pull ourselves together. “Sorry, sorry,” I gasped, “Go on. That just struck me as funny. . .” I babbled lamely.

The chemo class was just a warm-up for the “cancer sex” class. The river of chemicals racing through my body would create all sorts of changes, many of which would not be predictable. In particular, mucus membranes can become decidedly affected, whether they are in your mouth, your alimentary canal, your excretory system, or, well, other places.

The chemo-sex coach came in after Kristen and her stunned trainee left. She was elderly and sweet, and very compassionate, but honestly that day—the day before I started chemo—my sex life was not on my top ten list of concerns. Still, I took notes and tried to be a good student, if only to honor her sincerity and dedication.

When I recounted this educational offering to my Mindfulness in Health Care class several months later, we joked about inventing a chemo version of Match.com. “Welcome to Chemo Hookups. Temporary matches for your treatment months.” “Upload your photo today: We’re all bald!” Although we doubled over with laughter, something about the idea remains deeply touching to me. So many folks are single or have partners who can’t cope with the cancer. How wonderful to have someone *simpatico* at the end of the day to share treatment stories and then even dinner and bedtime? I think the mental health part of our insurance really ought to cover this.

One of the ways that I prepared myself for the first round of chemo was to pack kind of a day bag like you would for a trip to the beach, only without the beer.

I had had a quick tour of the chemo suite and was terrified. I couldn't have known that it was an unusual day, but most of the folks there who being infused were very ill. My heart broke open time and time again, as each four-patient pod of the suite offered up patient after patient, curled into him- or herself under layers of blankets. This is you in a few months, my mind kept thinking. This is your future. No—stop. Stay in *this* moment.

I decided to prepare by packing. They told me that the liquids used in the infusions would be either at room temperature or a tad cooler, and they can make you feel downright chilly as your body absorbs them, so I packed a comfy blanket and a travel pillow, as if I were off on an overnight flight to Europe.

Of course, the terror is that the chemo will produce uncontrollable vomiting. That was the image I had, anyway, from the past few decades of hearing about the process. (I won't leave you worrying here: mine is a completely vomit-free story.) Still, the idea of food was a scary one—what will feel OK in my tummy? What will stay down, and what will not? My mom had sent me a care package containing an assortment of ginger items, as ginger naturally soothes an upset stomach, so I had my ginger gum and ginger hard candies tucked into my bag. I had been warned that a chemo day was long (the first one was about ten hours). I would need to eat something, sooner or later.

Tom and Cathy would be spending the day with me, so I didn't expect to be bored, but I tucked a few books into my pack, especially Pema Chödrön's *The Places That Scare You: A Guide to Fearlessness in Difficult Times*. Also my knitting, and an iPod and earbuds.

I had put together a playlist on my iPod to listen to during chemo. I compiled hours of unrelated music, from the Beatles' cheerful "Here Comes the Sun" and sweet "Today" by John Denver, to the funny Weird Al's "Amish Paradise" and the groovy "Element Chant" by Spiral Rhythm. After some thought, I titled the playlist: Chemical Warfare. OK, I was ready. Bring it on.

Arriving for chemo day one was disconcerting. I felt great, physically, so it was counterintuitive knowing the drugs themselves would make me feel sick. After three weeks of scans and meetings and invasive procedures, looking at my x-rays, PET scans, CT scans, still it was hard for me truly to believe that there was a fist-sized mass growing between my heart and right lung, just hovering in there. Walking into the chemo suite seemed wrong, somehow.

My new port was ready in my chest, surgically tucked under the top layer of skin, but the glued-shut incision was still fresh and sore. Kristen explained to me that the chemicals are so caustic, a course of chemo would cause severe damage to the veins during an infusion. This new system, with the bottle-cap-sized port in the chest, from which a tiny IV tube was snaked under my skin, up to my throat, slid into my jugular, and then snaked through the jugular down into the superior vena cava vein, which pumps blood directly into the right atrium of the heart, was intended to avoid that particular damage.

While she was calmly explaining all of this to me, I was mentally hitting the brakes. “Hey, wait a minute here. The drugs are so nasty they’ll destroy my veins, so the ‘better’ option is to stick them straight into my heart? My *heart*, for crying out loud? Hello? Anyone else think this is freaking nuts?”

Kristen watched me flip out with her usual patience. She acted as if I were the only patient she’d ever had, and that she had never explained a treatment before—everything was gently tailored to my personal experience. “Yes,” she said, “yes, it does sound stupid, doesn’t it? But here is why it’s also genius.”

This upper right chamber of the heart is like a tropical getaway. Imagine a secret hot tub with a gorgeous cascading waterfall splashing down from above. Mmmmm, this chamber of the heart is like a tiny spa vacation in your chest. This is where there is the largest concentration of blood all in one spot, so that the drugs are immediately diluted as much as possible. “OK,” my brain conceded, “that sounds good.” It is also a fast-moving area, because that chamber is pumping

blood out just as quickly as it is filling up, so if you drip the chemo drugs into the waterfall, and they splash down into the hot tub, they are also quickly mixed with the blood and pumped out into the rest of the body. No waiting around for a long trip through the veins, burning everything along the way. The caustic drugs get mixed with lots of blood fast, and are on their way quickly to find those cancer cells and kill them off. By the end of her explanation, I was convinced. "Let's do this," I said.

The suite I was in was well designed. It was broken up into groups of four infusion stations, and each pod was your little chemo universe. There was a recliner chair for the patient, a chair or two for visitors, all the necessary medical apparatus, a table, a mini-TV, and a curtain for privacy. Once hooked up to the IV, I also had the option of grabbing my IV pole and wandering a little bit around the larger area, using the bathroom, checking out the snacks in the two small kitchens, visiting with others, looking out the windows, and so forth. We were allowed to roll ourselves to the end of the linoleum, but where the carpet started we had to stop. It felt a little bit like electric fencing for dogs.

My nurse was seasoned and no-nonsense, but she was also intensely committed to making sure my first day went well. I felt deeply cared for, as she took all the time I needed to talk and answer questions throughout the day. Also, being a first-timer meant I got the chair by the window, which afforded a little extra privacy as well as a stunning view of the gardens outside, designed for the very purpose of delighting people in the chemo suite, whether you were inside getting infused or able to step outside. Little touches like this garden helped in ways that are hard to articulate; it was a reminder of beauty, and the knowledge that strangers cared enough to design, build, and maintain a garden to delight patients. It was another reminder that a chemo journey is supported by innumerable hands, that each of us had a community around us, visible and invisible.

Propped in my chair, playlist booted up and ready, Tom and Cathy beside me, nervously waiting, I sat as the nurse started to hook up a

fat IV bag of bright red liquid. She explained to us that the Rituxan often caused an allergic reaction, and so I should pay attention to how I was feeling, and signal to her if I felt anything out of the ordinary. The drip was set at a glacial pace, and I watched it head down the tubing toward my heart.

Every now and then, as I continued to tolerate the infusion, my nurse would check my vital signs and then let me know she was turning up the speed of the drip. After about the fourth time, she said, “Okay, we are now in the region when most people will experience side effects, so I’ll be close by. Remember to grab me if anything at all seems to change in your body.” She was hooking up an IV on a fellow across from me, so even though I didn’t think I’d need her, she was reassuringly close.

Then everything happened so fast, it was hard to separate the different actions. Tom and Cathy and I were chatting away when suddenly I felt an intense itching on my uvula. I mused that I’d never felt that before, and then it hit me, *allergic reaction*. In the half second it took me to think that thought, I could feel my soft palate begin to swell and fall downward into the back of my throat. My nurse flew to my side, stopping the IV and immediately pushing Benadryl into my line. She also must have sent out some kind of alarm, because the next thing I knew, my chair had been tipped way back and I was surrounded by clinicians, nurses, and doctors. Through a bit of a fog, I could see Tom and Cathy, now pushed against the far wall, anxiously watching the buzz of medical activity.

The curtains had been drawn around me, but they fluttered as different people seemed to be peeking in. I could hear voices asking, “Who was it? Oh. That one in the chair? She looks OK.” Then Gianni was pulling up a chair beside me, smiling. “How are you feeling?” he murmured. I wanted to tell him that if this was how day one was going to go down, I was suddenly taking this chemo much more seriously. That’s not what came out, though, because my face didn’t really seem to be attached to anything I could manipulate with my brain. I

had been given such a wallop of Benadryl, I think I kept falling asleep during the questioning.

Eventually, with me still breathing and everything else having calmed down, the nurse explained that she could now turn the IV up full speed, since the reaction I had had would now prevent another reaction from occurring. Through my earbuds, Carole King was singing something about being far away; I agreed with her and fell back into a groggy sleep.

The rest of the drugs dripped without drama, taking so long that my nurse's shift ended and the only employees left in the chemo suite were a night-shift nurse and the folks mopping the floors. Finally I was unhooked and given sheets of directives for being in touch over the next few days. I'd already filled my prescriptions for the many drugs I needed at home, and Cathy, Tom, and I wearily wandered out of the hospital, leaving behind the sound of industrial vacuum cleaners.

Out on the sidewalk, we agreed we were ravenous. I was worried about eating, but we hadn't really had a decent meal all day. Nearby was a good Italian restaurant; we got a table there and ordered up plates piled high with food, talking perhaps a little too loudly in order to shake off the worry of the day. I wondered if I looked different on the outside. I couldn't believe that I could be pumped full of so much poison and still look exactly the same.

We headed back to my apartment. My tiny bedroom had an attached bathroom, but my information sheets said that for the next eighteen weeks, I should not share a bathroom with anyone if at all possible, because my bodily fluids could be classified as hazardous materials. Talk about feeling a little creepy being inside your own body. Tom and Cathy made up beds on the couches in the living room, and went to brush their teeth in the bathrooms in the hallway outside.

Fully exhausted, I dropped into bed and soon fell asleep. In the middle of the night, I woke up, wondering what it was that had roused me. *Oh. Oh.* I realized that my large dinner actually was not settling very well, and I was starting to feel queasy. Growing waves

of nausea seemed to be ebbing and flowing inside of me. I swallowed hard, and reached for the information sheets on the bedside table to go through my checklists; I realized that I'd forgotten to take one of the Ondancetron tablets before bed. Whoops. I went to the bathroom, chose the right bottle from my array, and swallowed down the tiny pill. That done, I went back to bed, marveling that before I was fully horizontal, the nausea had completely vanished. I was asleep again in moments.

The next day dawned, uncharacteristically hot and humid. Cathy, Tom, and I mostly napped in front of the fan throughout the day. Was everything really OK, or would I at any moment become ragingly ill? Kristen called midmorning to check on me, and I told her that the only thing I felt was hot and sticky from the weather.

My mom called, expecting to hear a worried report about how sick I felt, and was not quite certain we were being honest as each one of us told her I was feeling fine. My sister finally had to step into the hallway out of earshot of me to prove that she was indeed telling the truth. The next day was the same, and the next. I took my pills, I waited and watched, but each day I felt unpredictably OK.

I bumped into Gianni in the hospital hallway one afternoon about a week after the chemo day. He scanned my face, and said he thought I looked surprisingly well. I told him I'd been wondering if my having been a theatre person and (dare I say it) drinking alcohol in no small quantities throughout my teen and early college years had perhaps, in some way, conditioned my body to being cyclically poisoned and bouncing back? He tipped his head back and laughed out loud. "You know," he said, "it's a theory. The folks who seem to have the worst time of it are the ones who have never had any alcohol, never had any strong drugs before. They tend to get very sick. I don't know how you might continue to test this theory, but who knows? You might be on to something." Chuckling to himself, he squeezed my arm and then strode off to his next consultation.

It was also in these first weeks that my friend Joan, of the Cellmates, started to send me quick photos every day of something beautiful. Often, it was a flower. Occasionally, it might be a vista, or something in her yard. Not a big deal, not any huge message, just the photo. But they started coming every day. It was genius. When I least expected it, there would come some tiny reminder that a friend far away was thinking of me, was sending me a little cheer so that I wouldn't feel alone. My heart swelled each time. Meanwhile, other gifts and delights came my way. I can't recall who sent me the small pig that shot Nerf balls out of its nose, but it was a huge favorite in the chemo suite. The smallest things could light up my day, giving me pleasure for hours or days.

As I continued to meditate and read more books about how to unhook from unsatisfying patterns of living, I found my spirit growing lighter, and my heart for all people growing larger. Looking at anyone while out in public—man, woman, or child—could reduce me to tears. A curl of hair at the nape of a neck, a dirty Band-Aid on a chubby finger, a quick look exchanged between friends—all these things were noticed, and cherished, as I found myself freshly alive in the family of humans.

I found that I could greet each day with unconditional gratitude. Since I didn't know how long my good luck was going to last, I tried to get outside and enjoy the sunshine, and imagined that the sun was also working its healing on me from the outside in. I had been warned not to stay out in the sun too long, as the drugs would make me hypersensitive to sunlight, but it felt so good that it was hard to monitor myself.

I also bought myself a treat, a Toronto Maple Leafs jersey. That very first day, when the doctor at Student Health was explaining what non-Hodgkin's lymphoma was, he kept saying "NHL" over and over. I admit to having been in a total fog of denial at the time, but I truly wondered why he kept mentioning the National Hockey League.

Hours later, when I realized NHL were the initials of my cancer, I felt an odd connection. As a lifelong hockey fan, suddenly it didn't sound so scary, if what I had was just NHL. I got the jersey to remind me that someday in the future, NHL would again only stand for hockey, and I would be well and strong and on the other side of this.