THE BAD NEWS OUT OF RADIATION ONC

By Diane Kendig

> **“We are discussing life and death, and not in the abstract.”**
>
> --Vivian Bearing, a cancer patient *Wit* by Margaret Edson

The Pulitzer-prize winning play *Wit* renders palpable the medical treatment of a 50-year-old a college English professor with ovarian cancer. When I saw the play in the summer of 1999, I was struck by the callousness of her two oncologists, an established doctor named Kelekian, and his clinical fellow, Jason, in their dealings with their patient. Arrogant in the extreme, the two feign concern with a politeness thinner than veneer while fixating on their research and how her case factors into their numbers, how much pain they think she can withstand for the sake of their research.

So a year later, when my sister, a 48-year-old college professor in the Midwest, was diagnosed with Non-Hodgkin’s lymphoma, I almost expected *Wit*- like treatment, and I wondered that we didn’t experience much for two years. Whether at the chemo clinic, the local hospital, or three months in isolation in the huge university hospital, most of the doctors, technicians, nurses, and other healthcare employees we dealt with seemed genuinely caring and communicative.

Of course, my sister was not like Vivian Bearing, a cold, sarcastic loner. Daun Kendig was a performance professor, with an office of puppets and noisemakers, feathers, and her five-year old daughter’s drawings alongside the tomes of communication theory. And while Vivian spent her time pouring over John Donne poems alone, Daun with her students sat on buses and in hospitals to observe people in their everyday lives in order to create and perform plays based on those observations. Daun, a great communicator, was a people magnet, and perhaps, I thought, that was the key to the kind treatment she received.

But then, in January of 2002, after nearly two years of chemo and other treatments (including a stem cell transplant), Daun was sent for the first time to Radiation Oncology in the university hospital where she'd been treated for a year. And there, for six weeks, I saw unkindness unfold before me in more ways than any one play could depict. Surely Daun's two doctors, except for gender, could have been Kelekian and Jason. And the very space itself, its systems and communication patterns, were dysfunctional and inhumane.

Bound in Duct Tape

My first meeting with the Radiation Oncology Department came in January of 2002 when Daun was being "prepared" for her first radiation treatments the following week. Asked if I wanted to accompany her, I said yes and pushed her wheelchair into a room so cold it could have been the walk-in refrigerator of a restaurant except bigger, the size of a small amphitheater and empty. One technician told me to sit down in the far corner of the back while she wheeled Daun to the front, had her get up on a high table against a white wall, contorted her body into a cramped, awkward position, and then got out a roll of industrial gray duct tape.

As much as that awkward position, I recall the chilly silence in that chilly space. No one introduced themselves or gave any explanation or cheer as they began to wrap her in the tape that we have seen on kidnap victims, both dead and alive, in cop shows. Daun and I knew the tape from our father's furnace work, where the gray at least matches the ductwork metal. Stretched across her body like dirty snow, the tape did not match that glaringly icy white room.

If someone had just said, "Sorry for how this looks, but the exact position is important, and this works best," it would have been enough. Or forget sorry. We know about liability if you ever say you are sorry. Maybe factual. If they had said, “Now we are going to tape you into this position for seven to ten minutes so we can get the precise reading we need to do this procedure exactly. Do you have any questions? Are you ready?” Or Daun would have loved best, “You didn’t know that duct tape is used to treat cancer, did you?”

But there was neither humor nor any communication, verbal or non-verbal. Just the silence and the cold and the damned tape.

The technician left and I called to Daun, asking if she were okay.

“Yes, but that was weird, don’t you think?”

“Very weird.”

The technician returned behind a very officious woman who strode in, clearly above the technician in their hierarchy (and clearly way above us all, as she never acknowledged any of us). In her very expensive calf-length, brown paisley dress, over which she’d slung an open lab coat, she leaned in to examine some instruments, nodded once to the technician, and whooshed out of the room. Unlike staff members in *Wit*, who had to be reminded of the protocol to address the patient, this doctor never got such a reminder, or perhaps there was no such protocol.

Then I was sent out of the room, the technician behind me, and Daun was left alone in the cold, bound with duct tape, an image that will always trouble me. We were eventually released from Radiation Onc and told to return the following day for a scan, a scan that proceeded in a similarly silent way, contrasting to the many bone-, CAT-, and other scans Daun had undergone with friendly receptionists and staff members.

That morning, she was very sick from the large amount of awful fluid she had had to ingest before the 90-minute ride to the hospital, but no one addressed her clear discomfort. No one addressed anything. The woman who met us for the scan was young and armed with a book, which she set to reading as soon as the scan was under way for what would take—and now, she was actually speaking to us— “about 30 minutes, during which time, you should not move.” She plunked down and opened her book as the machine made a slow crawl above Daun’s body.

About 10 minutes into the procedure, the technician had not looked up yet, but then Daun whispered, “I think the machine has caught my sweater.”

Sure enough, the sweater was being dragged into the machine, which seemed to be ingesting it, just to see if anyone was looking. The technician, without a word, stopped the machine, took the sweater out, rearranged it, turned the machine back on and returned to her book as we returned to our 30-minute wait that began all over again.

Miscommunication All Around

For the next two and a half weeks, we drove to the big city nearly every weekday for a radiation treatment. One day I met the older of the two Radiation Onc doctors, a female we will call Dr. Y. While reserved and business-like with us, she was positively imperious in her dealings with the staff. She didn’t speak, she barked, when she spoke at all, and as nearly as I could tell, she never listened to anyone. When asked for clarification, she would bark her same confusing orders in the same confusing words until the staff backed down from her yapping.

One day in the waiting room while Daun was in the radiation room, I heard a technician on the phone with that doctor.

“No, I don’t understand Dr. Y. Do you mean—“

The technician, cut off, remained silent while loud gravelly sounds from the receiver reached even my ear. When the sounds were over, the technician bravely tried again:

“Yes, but I mean—“

Cut off a second time, she persevered with, “But—“

That last word was cut off by a response that sounded like a hailstorm on the other end.

The technician hung up the phone, unnerved, and shaking her head said, “I sure hope I got that,” as she flipped the switch to one of the radiation rooms—not my sister’s, and I hope if it had been, I would have reached across and broken her wrist to stop her. But now I think how it was the room of *some*body’s loved one, and perhaps I should have broken her wrist for them.

Ten Days Later

Dr. Y had a demeanor that suggested controlled seething when we met with her for what we were told would be a discussion on the status of the tumor.

“For one thing,” she began in a scolding tone, “Your DHL is sky high.”

At the time, we were confused, thought she meant HDL, Daun’s cholesterol rating rather than DHL, which we didn’t know was a lymphoma term. Normally, Daun’s doctors would have explained the new term, and we waited for an explanation of what this high number meant, but Dr. L was on a tirade as she then announced that my sister might be courting liver damage. However, Daun had been warned often in the two years of possible damage to her liver—not to mention heart, lungs, and of course, the bones that were already breaking like toothpicks. She was in a wheelchair with both legs broken at that point, one repaired with a sizable pin. It’s not that she didn’t take the warnings seriously, but her choices were to risk organ damage and possibly live or quit treatment and surely die. As the single parent of a preschooler, she had nothing but the greatest incentive of all, a mother’s incentive to live.

When the doctor paused, Daun finally got a question in edgewise: but what of the tumor? We were told we were here to discuss the tumor.

“The tumor is greatly reduced,” said Dr. Y.

In two years of work on that tumor, we had heard, “two times larger, “ “larger,” “no change,” but never had we heard, “The tumor is greatly reduced.” It seemed like great news.

Except that Dr. Y was furious, seemingly at Daun, as she left the room.

Just recently, I came across these lines from *Wit*, spoken by the character of the nurse, Susie, explaining the situation to Vivian: “Well, they thought the drugs would make the tumor get smaller, and it has gotten a lot smaller. But the problem is that it started in new places too…. I’m sorry. They should have explained this.”

They should have.

Marla’s Take

Marla was my sister’s colleague, her neighbor, and one of the four people outside of the family that Daun allowed in her room the last week of her life. In short, she was a great friend. A few days after our strange scolding by Dr. Y, when I couldn’t be in town, Marla accompanied Daun to Radiation Onc. This is Marla’s memory of the contrast between the Radiation Onc and the Lymphoma departments:

> *It was winter and freezing, and Daun was feeling so very sick after two weeks of radiation. We got to the parking garage and just getting to the radiation clinic was like a trek from Siberia. I remember thinking, “Can’t we do this any better?”*
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> *We were waiting in the room for the doctor to come in. I can’t recall his name, the younger guy, one of the medical fellows. Daun always referred to him as “Skippy” because of his sort of childishness. He was just inappropriate in every conceivable way.*
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> *First, he walked to the examining table and hiked his butt up onto it to face us and loom over us as we sat below, Daun in her wheelchair. His legs dangled, and he’d swing*

> *them nervously along with a sort of inane chatter, things like, "I guess you're not feeling so good, huh?" Daun answered quietly that she wasn't.*
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> *And then with that out of the way, he turned to me and discussed her situation, as though she were not even there. He never made eye contact with her as he talked to me, ignoring Daun, the way people don't talk to the handicapped or the very old, how they ignore them. And there we were, the two of us sitting very low, and him sitting up there very high.*

Usually Daun actively participated in any discussion with her doctors, but that day she felt whipped, and she remained unresponsive. Two weeks later, when she was alert and present, I saw her give Skippy a run for his money in the medical discussion department. And when she did, it became clear to us that he knew little about her case, came in with lines to deliver from Dr. Y and when pressed with a question, made up an answer that the lymphoma oncologist told us later was both categorically and specifically wrong. But I'm ahead of myself now, and of Marla, who continued:

> *Then Dr. Y came in, completely business-like in the worst sense of the word. What I remember most is that she was almost giving orders and like she was very rushed, sort of, "You do this," and "You do that," like talking with us was an annoyance. She was brusque and never sat down nor made eye contact. It was as though she were scolding us for something.*
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> *After we left Skippy and Dr. Y, we went to the Transplant Clinic. I remember the waiting room was large and packed with people, and I signed in at the desk.*
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> *Within moments, a young woman came out, scanned the room, found Daun, and came over to where we were. She crouched down, eye to eye with Daun, put her hand over Daun's hand and was so present as she asked, "Pretty bad day?"*

And then Daun just opened up and in just a few seconds gave her an account of the whole last rotten week, the overwhelming sickness and the medical system hassles on top of it.

"I am so sorry," the woman responded.

And then Daun smiled the tiniest bit for the first time that day, like someone had finally heard her.

I recall that contrast so clearly, one person towering over us, swinging his legs and the other, kneeling, listening to Daun.

Thirty-Five Times a Month

Harvard Medical School doctor Jerome Groopman noted in one of his *New Yorker* articles that oncologists have to deliver bad news to cancer patients an average of thirty-five times a month. They might have to tell them that cancer once in remission has returned or that a tumor has grown, or, in the case of my sister our last day in Radiation Onc, that "treatment has failed and no further treatment would be useful."

We didn't know that's what we would be getting when we set up what would be a final appointment with Dr. Y over the phone, and an assistant mentioned that Dr. Y would just be returning from two weeks at a conference in Hawaii. "Maybe she'll bring you a pineapple," he joked. So when she was nearly an hour late for the appointment, we wondered if she had missed her flight home. But no, a fellow reported at the end of the hour that the department that had performed the latest scan would not release it, so Dr. Y was going upstairs to view he scan.

Meanwhile, my sister's IV bag had run dry, and her blood had begun to run out and fill the tube. I went to the nurse's station to report this and the nurse completed a personal phone call about her date the night before attending to me while I stood below a very large clock above her station. So I know for sure that she chatted for ten minutes, and now I cannot believe I just stood there. I think I was so exhausted and undone, such a good soldier who for so long had believed like my sister that good behavior would get us off. As the nurse hung up the phone, she looked at me peevishly for the first time and said, “Is something the matter?” as though I were bothering her to ask where the coffee was. When I told her my sister’s IV tube was filling up with blood, she whipped out of her box and hurried down the hall.

At one point, Skippy came in and asked my sister to go to the hallway to be weighed. She had just been weighed that morning upstairs in her primary oncologist’s office, and it was hard since she was in a wheelchair, but such repetition was typical, so she wheeled out and hoisted herself onto the scales.

“You’ve lost seven pounds!” he shouted, turning, aghast. “You only weigh 105 pounds.”

“They just weighed me upstairs this morning, and I was 109,” Daun said.

“This is not good,” he said to my sister as though he had not heard what she said and told her to return to the examining room, for all the world as if she were being treated for anorexia and had not followed orders.

We returned to the examining room and continued to wait for Dr. Y to return with the CAT-scan results, but eventually she sent Skippy back instead.

Skippy, who had not seen anything for himself, reported second hand what he had been told by Dr. Y: that the CAT-scan showed some areas improved but some lymph nodes were “not as good.” They had treated as high in the body as they had seen any growth, but now there was a whole new chain—that was his word, a “chain”—high and moving higher up.

“What do you mean by ‘up’?” Daun asked.

And Skippy, as though she were a non-native speaker, lifted his hand in the air and said, “Up,” then lifted it higher and said again, “Up.”

“But what about the PET-scan just last week?” my sister asked. “That showed that everything was the same.”

“Oh well, a PET-scan,” he scoffed. “Well a PET-Scan is totally different. You can’t even compare them.” (The next day, Daun’s primary oncology doctor explained that in fact, they did compare them, and it was the comparison which showed that this growth was totally new, that in the intervening week the cancer had taken off like kudzu in her body.)

Then he informed us that Dr. Y, who was paging Daun’s primary oncology doctor, would return in a moment.

Dr. Y came in fifteen minutes later with Skippy and noted that Skippy had informed us of everything, which was that this treatment was not working and “On top of everything else, you’ve gone and lost weight.”

She said that she was not able to reach Daun’s primary oncologist, who would explain everything else the next day.

The Aftermath

I am reminded that the root of the “math” in the word “aftermath” means “mowing,” and clearly in the aftermath of that day we felt we had been mown down by the Radiation Onc department as we returned home that night. The next day after another 90-minute drive we received the bad news from the primary doctor who took us into a back room. She brought tissues, sat down, and said that “short of a miracle,” Daun was at the end of treatment, which was to say, her life. She could not tell us how long Daun had, of course, but it would be very soon, six weeks at the longest. She, and later her staff, wept with us and answered Daun’s question about palliative care, about the death itself, about the chance for that miracle.

They also listened to our account of what had transpired the day before, and the days before that, and they made phone calls to the hospital ombudsman to complain in our name. They asked us to call ourselves and file a complaint, but we had way too much to do to file a complaint in the following six weeks and one day of intense living before Daun died.

So now, many many months later, I give you our experiences with Radiation Oncology at Fairview Hospital at the University of Minnesota. Let them serve as my complaint.

(First published in *Under the Sun*, (Vol. XIV, No. 9) Summer 2009. ©Diane Kendig)