Primo Chemo

The treatment stinks. So does the patient

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The word alone conjures up all sorts of terrors—and not just for PWAs: Decades of “hopeless” patients have come to think of chemotherapy as “You’re dying anyway, so let’s bombard you with enough cyanide gas to kill an elephant, and see what happens.” And why not? When you’re desperate, in pain and getting worse day by day, you’re willing to take outrageous steps, even if it’s only a 50-50 chance.

Those are the odds I was offered four years ago. Did I hesitate? No—hesitation is for those who have a choice, and with an AIDS-related lymphoma tumor growing at the base of my spine, painfully paralyzing my legs, I had no choice.

I started the next day with a radiation appetizer, followed by the main course: Chemo. I’d go in early Tuesday morning, hook up to an IV drip and spend three hours being infused with four different bags of chemicals. Upon leaving, I was given a week’s worth of pills, and an additional week of self-administered injections—subcutaneous, not IV.

Despite some side effects—headaches, diarrhea, constipation, muscle aches and a bizarre out-of-body sensation that lasted for days—I was able to get on with my life, and the impact on my tumor was immediate. The pain went away; I was able to walk again. Somehow, my body tolerated the poison (I mean medicine) pretty well.

No one warned me about the most unpleasant side effect: I smelled like a rotting corpse. Remember, they’re putting all these noxious chemicals into your body to kill off massive numbers of rapidly multiplying cancer cells (not to mention almost killing you), and your body has to “bury its dead.” Every substance my body emitted seemed reminiscent of that pulp mill near Albany, Oregon that I remember from family vacations as a child.

Meanwhile, which side effect were the doctors concerned about? Hair loss. Puh-*leeze*. Yes, I lost all my hair, from pubes to eyebrows, and it saved me a good deal of time. I prefer being smooth. Now, there’s a side effect that I’d like to see prolonged perpetually.At the end of six months, I was declared “in remission”—they don’t use the word *cured*, but remission can last 50 years.

Or three. I returned last year for round two. Different tumor, this time in my stomach. They’d made progress in treatment options since the first episode. The dosage had been cut in half, and the side effects were proportionately diminished: After four cycles of chemo lite, my hair hadn’t fallen

out. Shucks.

Worse, I still had the tumor. The doc decided to change formulas from “CHOP”—an acronym for four chemicals with names that sounded like gasoline derivatives—to a more potent recipe referred to as “the Big Guns.” Instead of a quickie infusion, the Big Guns required a five-day hospital stay, with a continuous drip. I had to lie in bed with that damn IV pole attached to me from Monday to Friday.

After two rounds, I was a candidate for a padded room: Lying still has never been one of my skills. So I rebelled, prompting my doctor to produce a miracle that he’d had up his sleeve (or at least in his pocket) all along—a portable IV pack, about the size of a cell phone, which could be worn on a belt.

Suddenly, I was free! It was life as usual—as long as I was back at the hospital at 2 pm to have the chemo reservoir refilled. Just the simple fact of being able to sleep in my own bed—not to mention being able to eat at restaurants, instead of hospital food—would have made this device well worthwhile in my book. After two cycles, I can wholeheartedly endorse the belt-pack chemo kit as one of this century’s greatest advances in medical technology.

Dealing with the pain of the lymphoma wasn’t pleasant, but the dreaded chemo side effects proved to be a breeze. Funny that something as simple as being confined to a bed and connected to an IV pole for five days could break me, but now I know my limits. Though I can cope with pain and infirmity, if I can’t have my freedom, life is not worth living. It’s a relief to know that doctors are beginning to recognize the importance of such “intangibles”—especially for the patients they’re trying to almost kill.

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