Out on a Lymphoma

June 1, 1998 By Scott O'Hara

“You have a fifty-fifty chance of surviving the treatment” wasn’t exactly the best news my doctor had ever given me. If lymphoma hadn’t been causing me constant, intolerable pain for four months, I might have opted for quality of life. As it was, I just said, “Great, let’s get on with it.”

That was four years ago, and I’m still here...dammit! The tumors -- one on my spinal cord, the other next to my spleen -- faded after several months of intensive chemo. My body proved surprisingly (to the docs) resilient, and soon I was back biking, hiking, tending my garden and publishing my zines. Then, three years later, something different popped up. This time the warning came in the form of extreme heartburn -- like a duodenal ulcer that wouldn’t quit. After a colonoscopy and liver biopsy, my doctor decided it was in my stomach; an MRI and endoscopy confirmed what he’d suspected: More lymphoma. The gastrointestinal tract is a fairly common target for lymphomas in PWAs, so he wasn’t surprised, although he’d worried that it might be Kaposi’s sarcoma. “Either way, there are therapies,” he told me confidently. “You have a number of options.” This was a different doc, more optimistic -- enough already with talk of 50-50 chances. We started treatment.

That was a year ago. I’m still going through chemo, off and on. My doctor has acknowledged that the lymphoma will probably never disappear completely and I’ll probably have to keep doing this permanently. But I’ve been lucky so far -- the treatments aren’t too miserable. I can even say that I hope to stay on chemotherapy...oh, a couple of decades, at least.

Lymphoma is a fairly common cancer of the lymphatic system, the bodywide web of infection-fighting tissue. People with weakened immune systems are 40 times more likely to get it, and as many as one out of 15 HIVers does, usually non-Hodgkin’s lymphoma (NHL). That’s what I got. And there’s evidence that more PWAs will have NHL to look forward to as we live longer on cocktails that cause humps, lumps and Lord knows what else.

Lymphoma’s symptoms may -- or may not -- include night sweats, swollen lymph nodes, fevers and sudden weight loss (more than 10 percent). Since these often occur in PWAs for other reasons, they may be overlooked. Primary central nervous system (CNS) lymphoma may announce itself rather grandly, with vision problems and motor-control difficulties, but otherwise you may not know until the tumor starts to interfere with the most mundane activities. One tumor pinched a nerve in my spinal cord so my left leg went dead. Another swelled to the point where there was less and less room for food in my stomach and air in my diaphragm. No eating, no breathing -- how inconvenient.

Lymphoma would be easier to treat if it had an early warning system. As it is, you just have to watch yourself (without going crazy), and push for an accurate diagnosis when something weird is going on. This means a biopsy -- usually fishing up some flesh from an organ, but with CNS lymphoma, poking a hole in your brain. Luckily, Vanderbilt University researchers recently found that a PET (brain) scan can yield an accurate diagnosis, biopsy-free.

Complicating things further, lymphomas come in stages ranging from one (very limited tissue involvement at only one site) to four (very extensive tissue involvement at many sites). In order to identify the stage, it may be necessary to undergo one or more of the following procedures: X rays, CAT or MRI scans of the chest, abdomen and pelvis, a lumbar puncture (spinal tap), a bone marrow aspirate and biopsy or a whole-body gallium-67 scan.

Treatment options are...well...better than ever. Four years ago, it was CHOP or die. Actually, I first got radiation to “stun” the tumor; it worked for me -- within days, the pain was gone. But that procedure is not a cure. No, the best odds available to me were CHOPs, a mixture of four noxious chemicals pumped into your body in hopes of turning the site into the human equivalent of a toxic-waste dump to keep the cancer (and much else) from growing. For those not into anonymous injections: The chemo quartet known as CHOP is composed of cyclophosphamide, hydroxydaunomycin (doxorubicin), Oncovin (its generic name, vincristine, doesn’t lend itself to as apropos an acronym) and prednisone. The first three are given by infusion over a four-hour period; prednisone is in pill form.

CHOP comes with a charming array of potential side effects, including nausea, vomiting, fatigue, diarrhea, hair loss, peripheral neuropathy, mouth sores, jaw pain, constipation, swollen or sensitive gums, and, finally, marrow suppression that can decrease production of white blood cells (neutropenia), red blood cells (anemia) and platelets, and increase risk of bacterial infections. As any been-around-the-block PWA knows, there are drugs to counter many of these side effects, and drugs to counter those drugs’ side effects...ad nauseam, as it were. (See When Chemo Calls)

Don’t say I didn’t warn you: Hydroxydaunomycin’s a heart-stopper, literally. And permanently. But this happens only if your lifetime dose exceeds 550 mg/ml, a level that, my doctor assures me, I have yet to reach. A study in Britain is substituting the kinder, gentler drug Idarubicin for hydroxydaunomycin in the cocktail, but it isn’t yet available in the United States. In an effort to minimize side effects, I tried a reduced dosage of CHOP, which, according to my doc, works just as well as the higher one. It didn’t make me puke; my hair didn’t even fall out. On the other hand, it didn’t shrink the tumor much, either.

Next I tried acronym CDE. This combo has the same two key ingredients as CHOP plus a new one, etoposide. So it should properly be known as CHE, but the H’s lab name, doxorubicin is used -- apparently marketers feared that the CHE acronym might lead to a patient revolt. Whatever else it is, CDE is potent enough that you can’t take it all in one pop. The infusion is spread over a 96-hour period, given once every four weeks for a maximum of eight cycles. Combined with G-CSF (Neupogen) to counter chemo-induced immune suppression, results to date show that CDE may be more effective and less toxic than the standard treatment. And the infusions are tolerable with a portable pump that you can carry around. Otherwise, it’s hell -- lying in a hospital bed for four days, immobilized. Take my word for it: Portable is the way to go.

So far the hassle has been worth it because the etoposide seems to be working. At least for now. The word *cure* never crosses my doctor’s lips, but he was happy enough with my progress to give me a three-month vacation from chemo, during which I felt as healthy as I’ve ever been. So, viva CHE!

My body has held up remarkably well under this barrage, so my personal experience with some of the nastier side effects isn’t all it could be. Yes, I get anemic and neutropenic. For about two weeks after each treatment, I have to be especially careful, because even the slightest cut anywhere on my body can blossom into an instant infection. I keep a tube of antibiotic ointment on me at all times, and I’m not afraid to use it. I’ve had to go into the hospital twice with strange infections; I don’t ever want to go back.

Aside from the low blood counts, my only side effects from chemo have been constipation (unpleasant, but hardly life-threatening) and a need to spend a little more time in bed. My hair got thinner...and thinner...and thinner. I waited for it all to fall out; eventually I just said, “Oh, the hell with it,” and shaved my head. Everyone I’ve talked to reports nausea with any form of chemotherapy. Guess I have a cast-iron stomach.

There’s a laundry list of other therapies, most including a chemo regime. M-BACOD -- low-dose methotrexate, bleomycin, Adriamycin, cyclophosphamide, Oncovin and dexamethasone -- is on my doctor’s B-list (“When this one stops working ... ”), but he’s holding off because of its toxicity. Other docs prescribe this sooner, using a low dose that’s equally effective, along with GM-CSF to counter the white blood cell loss. For those whose lymphomas survive standard weapons, there are a few experimental protocols: Subcutaneous injections of interleukin-2; topotecan, by infusion for 21 days; and weekly infusions of MGBG (methylglyoxal-bis-guanylhydrazone -- say that three times, quickly! -- or mitoguazone), a supertoxin that may be tolerable in low doses and that has a long half-life (it stays in the body longer), can slip into the cerebrospinal fluid and doesn’t suck out your bone marrow. And brand-new in the showroom: A monoclonal antibody, aka Rituxan.

One problem with Rituxan is that it’s approved only for a low-grade lymphoma uncommon among PWAs. Lymphoma is not a single disease -- it’s 17 unique (but related) ones. The basic division is between Hodgkin’s disease and non-Hodgkin’s lymphoma, or NHL. NHL is subdivided into at least a dozen types, according to the cell that’s involved, such as CD4 cells, B-cells (that’s my type), mantle cell, large cell and lymphoblasts. And each tumor is graded -- low, intermediate and high -- based on rate of progression. Cancer is a school in which grades count, mainly because certain treatments -- Rituxan, for one -- are approved for only one. Trials in Europe are testing the drug’s effect on high-grade tumors, but reports are mixed. This experimental treatment isn’t of much interest to my doctor, since PWAs tend to have tumors that live in the fast lane. Ironic, isn’t it? (Rituxan’s other problem is the $15,000-per-treatment price tag -- steep enough to raise the dead. ACT UP/Golden Gate is currently elbowing Genentech to get it down.)

The nice thing about NHL ("the cancer of choice, if you're going to choose cancer") is that there seems to be a new treatment weekly. Lymphoma research has benefited greatly from the disease's ties to AIDS, in terms of funding and interest. No fewer than seven studies are ongoing or recently completed: DaunoXome, 2-CDA, topotecan, Mitoxantrone, MGBG, a B43-PAP antibody made from pokeweed (only open to patients under 30) and several wave-of-the-future immunotherapies.

Because Epstein-Barr virus (EBV) is found in almost all primary brain lymphomas and on the surface of some tumor cells, another therapeutic approach is to attack the EBV antigens. In one study, CD8 cells taken from either the person with the lymphoma or a compatible donor are exposed to EBV antigens to produce EBV-specific killer CD4 cells, and then these are cultured, grown and put back into the person with lymphoma. The theory that these anti-EBV cells will destroy the tumor cells remains just that, a theory.

I've also checked out alternative -- oops! I mean complementary, as the woman who runs the local acupuncture clinic pointedly corrected -- medicine. Somewhat to my surprise, the acupuncturist didn't try to tell me what wonderful treatments she could offer for lymphoma; instead she said that Western medicine was the place to start. Then, to handle the stress, pain and other side effects -- of either tumor or chemo -- acupuncture can be helpful.

So I had needles stuck in me. I did not know, frankly, what was supposed to happen; perhaps that was the problem, because nothing happened. I went back, though, and the acupuncturist was very specific about what I should look for (relief of pain, right...here). I'd been having difficulty sleeping, eating, breathing -- this tumor was getting out of hand! So I lay down and the acupuncturist poked me full of needles again. This time, when I got up, the pain was gone. No, it didn't stay gone. But that night I was able to sleep. Now I'm actually looking forward to my third acupuncture treatment.

Last thoughts: Eat wholesome meals (lots of veggies!), get exercise, stop already with the coffee. (Although my doc assures me that coffee has no effect on my tumor, he's not the one who has it...and I can feel a big difference when I abstain. Which I've been doing, lately, as the pain has gradually come back.) Ditto with other questionable habits: You don't really need Mommy to stand over you and tell you not to drink or smoke, do you? And one more thing: Get a life. Not that I lacked one before lymphoma, mind you, but when I informed my doctor that I wouldn't have another relapse anytime soon because I was simply too busy, he was pleased. According to him, that's one of the best predictors of long-term survival: Having something in your life that really excites you. For me, it's writing. For you, it might be crocheting.

So I go about my post-chemo, post-lymphoma life as if nothing has happened. Nevertheless, the memory of walking alongside death all those months has stayed with me. I made friends with my mortality during that time -- I had to accept that, yes, this might be the end. And it was good for me. I don't recall any high drama; it was all very real and down-to-earth. Death or life: Take your pick. The only difference is how entertaining you make the interim. Chemotherapy is many things, but it's certainly not dull.

The bottom line is, there are options to deal with lymphoma. It’s nice to know there’s finally more than one treatment. Try them out for yourself; I don’t have time to do a taste-test. People who fail one protocol can move on to the next (assuming they’re still alive). What good is sitting alone in your room? This isn’t a hopeless disease anymore, unless, of course, you believe that life is hopeless, we’re all doomed anyway, etc., in which case cancer is the least of your problems.

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