



Rancho Los Amigos

Post-Polio

Support Group

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Facing Cancer: A Personal Story

By Richard Daggett

Just because we've had polio doesn't make us immune to other health problems. I have a friend who had polio and then developed multiple sclerosis. I have two other friends who had polio and now have acute gastro-intestinal problems. Many polio survivors I know are dealing with cancer and all the life altering aspects that a diagnosis of cancer can bring. The following article is an account of my own struggle with a cancer diagnosis, and the steps I've taken to mitigate some of the side effects of treatment.

In February 2005 I had a biopsy of my prostate and was given the diagnosis of cancer. This came after two previous biopsies that were cancer free. The initial prognosis was not good. I tried to keep a positive outlook, but it seemed that with every new test the prognosis got worse. I was dreading each doctor appointment. Additional tests were ordered and these later results were more hopeful. My urologist recommended treatment consisting of androgen-deprivation therapy and radiation.

Since I like to be as informed as possible I began to research treatment options by talking with other men who'd had prostate cancer. I also began searching the Internet and I read several articles and books.

(Continued on page 2)

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(Continued from page 1)

I decided that surgery was not the best option for me because of my particular polio complications. I learned that both androgen-deprivation therapy and radiation can cause fatigue and weakness. The fatigue I could probably handle, but I am already weak so any increased weakness would interfere with my diminishing independence.

In my research I found an article in a medical journal indicating that a regimen of strenuous exercise could reduce the weakness associated with cancer treatments. Strenuous exercise? That wouldn't work for me. I get about as much exercise as I can tolerate just brushing my teeth, feeding myself, and standing to transfer.

Just in case I misunderstood the article, I asked Dr. Jacquelin Perry to check it. Although Dr. Perry is retired, she still has a consulting role at the polio clinic of Rancho Los Amigos National Rehabilitation Center. I've known Dr. Perry for over fifty years and feel blessed to have her as a resource for post-polio issues.

Dr. Perry read the article and then telephoned me the next day. She said it was possible that a similar exercise regimen might work for me, excluding the "strenuous" parts. I was assigned a physical therapist who designed a program tailored to my needs. This was based on my concerns about losing the ability to transfer unaided.

I was given three different exercises:

- Extend my legs from the knee, focusing on my quadriceps.
- Lift my bottom off the bed, focusing on my gluteus muscles.
- Lift my head off the bed, focusing on my abdominal muscles.

I held each effort for a count to five. I was told to slowly work up to three sets of eight repetitions, and do the exercises three days a week.

The knee extension exercises were relatively easy. My legs, even as weak as they have become from PPS, are still my most functional extremities. Lifting my bottom off the bed became difficult before I finished three sets, two was about my limit. I have never been able to lift my head off the bed, but I still worked at the routine, feeling my abdominal muscles contract.

(Continued on page 3)

(Continued from page 2)

I started these exercises about the same time I started androgen-deprivation therapy (Lupron injections, a testosterone suppressant). My radiation treatments began about a month later. I chose Intensity Modulated Radiation Treatments. This is well-focused, external beam radiation. The radiation treatments brought their own set of problems. How was I going to get on the treatment table? I can stand to transfer, but the table was much too high. There was no way that I could climb or boost myself to that height.

We tried a Hoyer-style portable lift, but there wasn't enough room beneath the treatment table for the lift's legs to fit. A temporary solution was to have the radiation staff pick me up and transfer me to the table. I'm not heavy so this worked for the first few transfers. My concern was that their hands might slip, or they might strain a muscle and decide they didn't want to do this anymore.

Since necessity is the mother of invention, I "invented" a transfer device. I took a small bed sheet to a local upholsterer and asked him to sew handles made of webbing to the corners of the sheet. The webbing extended under the sheet, from one side to the other, reducing the strain on the sheet itself. Each morning I would place this transfer device in my wheelchair and sit on it before I left for my treatments. When I arrived at the radiation facility the staff grabbed the sheet by my improvised handles and safely lifted me on to the table.

My radiation treatments were daily (five days a week) for nine weeks. I scheduled these for the morning so that I could still plan other activities. I felt that part of my coping regimen would include having some enjoyment. I didn't want the treatments to take over my life. It is easy to become consumed by a cancer diagnosis and neglect the things that make living worthwhile. I made a conscious effort to think positively.

The radiation facility was a twenty-minute drive from my home and the treatments took about fifteen minutes, plus an additional twenty minutes preparation time. During the radiation treatments I continued my exercise regimen. I also tried to watch my diet. It would be counter-productive if I put on extra pounds.

Radiation to the prostate can cause urinary pain, urgency, and hesitation. It can also cause diarrhea. I developed quite a bit of the pain, urgency, and hesitation after two weeks of treatment. These symptoms were relieved with medication. I

(Continued on page 4)

(Continued from page 3)

was never troubled with diarrhea.

Fatigue set in about half way through the radiation treatments. Some days, especially in the early afternoon, I felt as if I would fall asleep sitting in front of the computer. Fortunately, these episodes faded. About a month after the treatments ended the greatest part of the fatigue was gone.

I continue my exercise regimen to this day but it is difficult to accurately assess the full impact. In some areas I feel I am a little weaker. Is this caused by the cancer treatments, or is it just the “normal” progression of post-polio syndrome? I don’t know if there is any way to tell.

When I started this journey one of my main concerns was losing the ability to transfer unaided. Even that assessment is complicated because I was fitted with a new leg brace during my nine weeks of treatment. It certainly is more comfortable, but it also feels different. My transfers became more tentative. I wondered if this was because I wasn’t accustomed to the new brace, or because I was getting weaker. As I’m writing this, my ability to transfer has improved. I’m not quite back to the easy transfers I had before, but I now believe the problem was just getting used to the brace.

The exercises have definitely helped in other areas. I can move around in bed more easily and I’ve lost an inch in waist measurement. This is not spectacular but it is welcome. I probably should have started this regimen years earlier, when I first began using a power chair full time.

When I was first diagnosed with cancer I felt like someone hit me with a club. But I did my research and chose what I felt were the best treatment options for me. It is too soon to know how effective these treatments have been, at least for the long term, but my latest tests have been encouraging. I’m feeling good and I’m hopeful. A person shouldn’t ask for more than this.

If anyone would like more information about my treatment choices, or share their own experiences, I can be reached at:

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