

## A TIME FOR SHARING

It began the summer of 1996 with an intermittent swelling on the right side of my neck. My Las Vegas internist suspected an infection and began a course of unsuccessful antibiotics. The next step was an MRI. The pictures showed a soft tissue mass in my neck, possibly a necrotic lymph node. But it wasn't to be that easy.

A week later the mass was removed and biopsied. The biopsy showed cancer. I was stunned. I was further discouraged upon learning the neck was not the primary site. Locating this primary site was imperative. The search began immediately. After several tests a tumor was located at the base of my tongue, uncommon in a nonsmoker; but I had been a heavy drinker for many years.

Through a close friend, I learned of a prominent head and neck surgeon at the Methodist Hospital in Houston, Texas. I headed to Houston for a second opinion.

In Houston, I was told that due to the tumor's location, it could not be removed. The initial biopsy was inconclusive. I underwent a second biopsy; again, it was inconclusive. The primary site was not identified.

I returned to Las Vegas to start external beam radiation therapy to be followed by a radical neck dissection. Upon my return to Las Vegas I had a CT scan. The radiologist diagnosed another tumor in my neck and a needle biopsy showed that it, too, was squamous cell carcinoma. I returned to Houston.

Back in Houston, I underwent a radical right neck dissection at which time 53 lymph nodes were removed. A partial left neck dissection was also performed, removing 20 lymph nodes. Pathology reports showed only two nodes were involved. My first good news in weeks. Still intent on finding the primary site, the surgeon removed additional tissue to biopsy and finally confirmed the base of the tongue as the primary site. It had metastasized to my

neck. Since the primary site of my cancer had been determined, I was offered an alternative to the standard technique of external-beam radiation. This alternative known as the Peacock System of Intensity Modulated Radiation Therapy (IMRT) might reduce the incidence of the known side effects of radiation therapy.

This was one of several alternatives suggested by the radiation therapy department of The Methodist Hospital. IMRT is a relatively new method of radiation delivery that would have a minimal effect on the salivary glands. It had been used on only one other occasion for base of tongue and in that case, it had not been successful.

My prognosis was poor; but, if I survived, the Peacock System of radiation therapy would leave me with functioning salivary glands. Having natural saliva was a significant quality-of-life factor and a major consideration, especially given my relatively young age of 49. I made the decision to undergo Intensity Modulating Radiation Therapy.

The process included surgically implanting two screws in the top of my skull, which were used to immobilize me during the delivery of the radiation. (This procedure is not always indicated. The site of the tumor will dictate the method used for immobilization.) The radiation was delivered by computer to the specific site of the tumor. This allowed treatment of the tumor with minimal long-term effects on the salivary glands.

I moved to Houston for the seven weeks of treatment. Daily, they treated the base of my tongue with IMRT and then later each morning I had conventional external beam radiation on my throat and neck. I lost all sense of taste almost immediately. After a few sessions the swelling at the base of my tongue felt as though I had a golf ball in my throat. The effects of the radiation treatment are cumulative. Consequently, it became almost impossible to swallow anything over the course of

treatment.

I wasn't in any pain but I felt that I was basically dying. All I did was try to sleep, get up each day, and go for the treatment. Getting myself to the hospital was the one and only thing I had to do each day. There was never any question of not doing that; it was literally a life or death thing. The treatments weren't painful although the delivery by this method was unpleasant. Each treatment lasted only about fifteen minutes but I was immobilized. I wore earplugs to deaden the sound that the linear accelerator made.

When I began treatments, I weighed 225 pounds; I weighed 175 pounds at completion of the treatments. Looking back, I know I made a mistake when I declined the feeding tube that was recommended. The weight loss would probably have been reduced by about 40% and I would have been better off, nutritionally.

I was quite debilitated and had almost no strength at all by the end of the radiation period. Just after New Year's, 1997, I returned to Las Vegas in a wheel chair to begin my rehabilitation. At this point, I had barely enough strength to get out of bed. I had home care IV fluids every other day. I still had no appetite or sense of taste and swallowing was almost impossible; essentially I had to learn to swallow all over again. Also, my saliva functions were poor, making eating difficult. I made myself eat yogurt and oatmeal, things that, like eggs, were very soft and easy to swallow. I remembered that okra was slippery and began eating boiled okra because it would slide easily down my throat. I soaked bread in soup and ate that. Slowly, I began to improve.

I was getting stronger and I knew that if I could exercise, my body would respond. I began working out at a gym and worked with a trainer three days a week. My muscles were so atrophied that I had to start with two-pound weights. I enrolled in physical therapy and went two days a week

for scar massage and upper body exercises. I monitored my weight and set a weight-gain goal of five pounds per month. I forced myself to eat to live and to do a little bit more on the treadmill each day. I knew I had to do this in order to recover.

Gradually I gained weight. One pound at a time, with forced eating three to five times a day. After 4 months I had gained 15 pounds. In the fifth month my taste began to return. First salty, then sweet and little by little my saliva output improved. Gradually my strength returned and I gained a total of 30 pounds. I can now swallow with no difficulty and have no speech problems. My saliva has returned to normal. My thyroid was affected by the radiation but the resulting hypothyroidism is corrected by daily medication (Synthroid). I return to Houston ev-

ery three months for a CT scan, chest x-ray, and blood work and have had no recurrence of the disease.

I know that I have been extraordinarily fortunate. Not only have I so far survived the battle against the cancer, but I suffer none of the common serious side effects of radiation therapy that can so adversely affect one's quality of life.

My good fortune is due to the Peacock system of Intensity Modulated Radiation Therapy. The FDA approved this delivery system of radiation in 1996. It differs from conventional radiation therapy in that it can beam a high dose of radiation that conforms tightly to the tumor itself. The radiation is conformed to the tumor by a specialized computer program. Difficult-to-reach tumors such as those in the head and neck

can be treated with new levels of accuracy. In addition, significantly higher radiation doses are possible. At the same time, the ability to specifically target the radiation to the tumor reduces the radiation exposure of surrounding healthy tissue and organs, greatly reducing the chances of side effects that are common with conventional radiation delivery.

Squamous cell carcinoma, the most prevalent type of cancer in the head and neck area, affects more than 40,000 individuals in the US annually. In my opinion, every one of them should have access to information about Intensity Modulated Radiation Therapy. ■

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