

I Survived Bladder Cancer By Vincent E. Sussman

<http://survivorofcancer.homestead.com/>

Sunday, October 3, 1999

Today, it is a beautiful day. I just returned from my two-mile walk and feel refreshed and fairly calm. Tomorrow, I check into St. Raphael Hospital in New Haven, Connecticut. On Tuesday, October 5, I will undergo a serious operation to remove my bladder and replace it with an exterior plastic bag. Two months ago, when I was going out to play golf, I noticed my urine was wine colored. It appeared to be blood. My golf game was worse than usual. When I returned home, I mentioned the blood in my urine to my wife, Rhoda. She was quite upset and told me to call my doctor immediately.

The earliest appointment I could schedule with my urologist was several days later. I was told to bring a sample of urine to the lab for testing. The tests were negative for infection. Although my urologist, Dr. Ralph DeVito, could not find any problem, he set up an appointment for a cystoscope. This was done a week later and he observed what appeared to be a polyp on my bladder. He ordered tests for a CAT scan, but my HMO refused it because my PSA was normal. Instead, he ordered an ultrasound and an IVP (Intravenous Polygram). The tests confirmed an obstruction in my bladder. The procedure to remove the "polyp" would be done as an outpatient. If it were more serious, I would have to stay over.

On Tuesday, August 2, 1999, I checked into St. Raphael Hospital. The "polyp" turned out to be a number 4 cancer. I stayed in the hospital for three days. The pathology report confirmed the cancer. My doctor ordered a CAT scan. This time my HMO approved it. The CAT scan revealed that the cancer had not spread. It was limited to the walls of my bladder. My urologist wanted to operate within two weeks. It was just two weeks before my 80th birthday and I was not ready. I wanted a second opinion.

My son scanned the Internet for information on bladder cancers. Each year nearly 55,000 men and women in the United States learn they have bladder cancer. Possible risk factors include smoking and exposure to carcinogens in the work place.

As a research chemist and plastics engineer for fifty years, I had been exposed to chemicals, which were thought to be harmless. Many were subsequently found to cause cancer. This was before OSHA regulations. Today, chemicals used in the workplace must have an MSDS sheet (Material Safety Data Sheet), which states the tolerance and risk factors associated with these chemicals and how they can be safely handled.

I set up an appointment to see an oncologist who confirmed my doctor's recommended procedure. The bladder would be removed. The two ureters coming from the kidney would be joined together with a piece of my small intestine. A piece

of my intestine would protrude through my abdominal skin conducting the urine into a pouch. The protruding intestine, called a stoma, would look like a red button.

I was now ready, but since this was to be a long operation, about six or seven hours, there would be two surgeons involved. I had to wait seven more weeks for the doctors and hospital to coordinate their schedules. The earliest date was October 5.

I continued my normal activities, walking regularly, attending meetings and seminars and playing golf. To get through this long wait, I decided to use my scientific skills and document events as they occurred in the hospital and beyond. I would be a player in the care of my health.

Monday, October 4, 1999

I arrive at the hospital at 1:00 PM. After showing my identity and HMO cards, I have a meeting with the anesthesiologist. He describes the procedure of giving the anesthesia and explains how my vital signs are to be monitored during the operation. I go to my room and change into a hospital gown. Since I have a pacemaker, I am in the cardiology wing instead of the urology wing.

Tuesday, October 5, 1999

I am wheeled into an area with about six other patients. One by one they are taken away. I am hooked up to an IV. That's the last thing I remember.

When I awake, I see a line of conveyer belts and hear that I would be put on a treadmill and injected with chemicals. I go bananas. I start to scream, "Don't kill me." I call out, "Rhoda, they want to kill me." The nurses tie me to the bed and try to subdue me. Later, I am told that this behavior is a reaction to the morphine, but I think that it was triggered by an event that occurred ten years ago.

A dear friend of mine had been in an automobile accident and was recovering in the hospital. His wife was at his bedside when a nurse came in and put something in his IV. "What are you giving me he asked?" She looked at his chart and said, "Oops, it's for another patient." My friend told his wife that he sees sparkles and bright lights. Within minutes he was dead.

Wednesday, October 6, 1999

I am wheeled out of the intensive care unit to my room. I share the room with a patient who had a burst aneurysm and almost died on the way to the hospital. He had a 4-way by-pass. He complains that he is hot although he is near the window. I am always cold. He has a lot of pain and requires high doses of painkillers. I am lucky. I have minimal pain. I am hooked up to an IV and have a tube under my nose feeding me oxygen. I am also hooked up to a heart monitor. A plastic bag acts as my bladder. It is connected with a flexible plastic hose to a large plastic receptacle, which stores my urine. The urine is red.

My wife hired a special duty nurse on the night shift named Leatrice. I will have her

with me for three nights. Leetrice is able to get me additional blankets to keep warm. Tomorrow, my roommate will be discharged and I will move to the window side of the room closer to the radiator.

Thursday, October 7, 1999

A new roommate, Richard, arrives in my room. He is a full-blooded Native American with a round face and thick black hair. Richard is 52 years old and weighs over 315 pounds. He had gone to his doctor with slight chest pains and was immediately sent to the hospital to have a 4-way by-pass. He tells me that both of his parents were dead of heart attacks by the age of 45.

He has a great deal of pain and is given narcotics to control it. He is always hot and wants the thermostat turned down. The hospital provides him with a big circulating fan. Leetrice keeps finding more blankets to keep me warm.

I have several visits from members of the clergy. One priest offers to give me communion but he notices the yarmicka I am wearing to keep me warm. He wishes me well and leaves.

The food at the hospital is terrible. I have no appetite and eat very little. Nurses come around regularly to check my pressure, temperature and the oxygen content of my blood. They work with rubber gloves and disposable instruments.

I do not sleep well. I am constantly being awakened and feel like a pincushion. They are jabbing me with saline solutions and antibiotics. After four days with little sleep, I ask for a sleeping pill.

Monday, October 11, 1999

I am feeling a little stronger, but when I get out of bed to walk I feel faint. The nurse is called. She takes my pressure. It is 90/60. With medication my pressure is usually around 125/80. The nurse says I have orthostatic hypertension, which means that my pressure can go down thirty or forty points when I go from a horizontal position to a standing position. She suggests I get up slowly and exercise my legs and feet before standing. This appears to solve my problem.

Tuesday, October 12, 1999

The pathology report is good. I will not require further cancer treatment. I can leave the hospital tomorrow.

Wednesday, October 13, 1999

The nurse comes in and removes my catheter. It had functioned as a drain to remove my body fluids. I am detached from my overflow bag. The pouch against my body will collect my urine. The IV has been disconnected. I am now mobile.

As I stand up I feel my urine leaking. The nurse checks the pouch and says that everything looks secure. The leak is coming from my penis. I am told this is

normal. After the catheter is removed it can take several days for the body fluids to drain.

The physical therapist tries to teach me to use a cane. I am supposed to hold the cane on my good right side, and then step with the cane, then the left leg, and then the good right leg. I have more problems learning to use the cane than walking without it.

Cindy, the urostomy nurse, comes to show me how to put on the pouch. She cleans the skin around the stoma using a soft paper. She dries the skin and then places the pouch over the stoma and presses it against the skin. The pouch consists of an adhesive skin barrier with a hole in the center to fit around the stoma, and a plastic bag to contain the urine. This is a one-piece pouch.

Rhoda comes to the hospital early with my clothes and a tuna fish sandwich from the hospital cafeteria. We are scheduled to leave at 4:00 PM. I change and we wait. Finally, a little after 4:00 p.m., the driver arrives with a wheel chair and we leave. Within twenty minutes, we are home.

I am able to climb the stairs with no help. I change into my pajamas and go to bed. As I lay down, tears start to roll down my cheeks. I have a sudden burst of emotion and start to cry like a baby. It is good to be home.

After my rest, I have my first meal at home, Rhoda's chicken soup with vegetables, and for dessert, ice cream and chocolate pudding. When I went to the hospital, I weighed 155 pounds. Now I am 135 pounds.

Thursday, October 14, 1999

My first night at home I dream about Brooklyn, New York, where I was born. I see street maps of the old neighborhood and meet friends of sixty years ago. I sleep very well.

Saturday, October 16, 1999

My appetite is fair. I am still feeling weak. Last night when I went to bed I felt wet around the pouch. It was leaking. I have worn it for three days.

Rhoda gives me towels and we prepare to put on a new pouch. First the sheet and my pajamas are changed. Then the pouch is put in place and we go to sleep.

Sunday, October 17, 1999

It is morning and the pouch is leaking again. A visiting nurse comes to the house and takes my vital signs and case history. She says the HMO will allow an aide to come for one hour, twice a week to clean me and do light housekeeping. A nurse will also come twice a week to check my blood pressure, take my temperature and assist with the pouch.

Later that afternoon Shirley, the Ostomy Queen, as she calls herself, comes to show me how to put on the pouch. She goes through the procedures using Unisolve™, a solvent wipe, which cleans old adhesive from the skin, and Skin Prep™, a wipe to provide better adhesion to the skin.

Monday, October 18, 1999

Today, I have an appointment with Dr. DeVito. The nurse removes the staples that hold the incision together. The doctor removes the Penrose drain, which comes out of the stoma. As he presses around my body, he notices a bulge, which could be a hernia. This could be serious. It could have occurred during the operation.

I am taken by wheelchair to a general surgeon in the next building who sends me for x-rays. He presses his fingers around my abdominal area. I have a slight pain. Observing the x-rays, he is unsure whether it is a hernia and said we should watch it for a few days.

Tuesday, October 19, 1999

The aide, Ellen, comes to the house and gives me a refreshing massage and sponge bath. She also cleans my room and bathroom.

Thursday, October 21, 1999

It is 4:30 AM. I am awake. The pouch is leaking. I wake up Rhoda and we change my pajamas and the bedding and put on a new pouch following Shirley's instructions. I take a Valium and sleep the rest of the night.

Later that morning, I decide to start an exercise program. The length of my house is sixty feet. I have a clear, straight path of fifty feet from one bedroom to the living room. I start to walk this distance several times a day. The first day I walk half a mile. I will increase it every day.

Saturday, October 23, 1999

The pouch is leaking again. I call the company that supplies the pouch and accessories and learn that the adhesive remover is to be thoroughly washed off and dried before the Skin Prep™ is applied. This solves the problem of premature leakage. The company says that they will send me a 2-piece pouch that might be easier to use.

Monday, October 25, 1999

I have appointments with Dr. DeVito and the surgeon. They are satisfied that I don't have a hernia. My incision is healing nicely.

Wednesday, November 3, 1999

Ellen, the aide, comes for the last time and cleans me and gives me a massage.

This makes me feel wonderful. My appetite is back. I drink whole milk and eat rich foods. I have gained several pounds. I now walk a mile a day in my house. I take frequent naps.

Monday, November 15, 1999

Rhoda and I go to an Ostomy Support meeting. Eleven people, including spouses show up. Each cancer survivor has a story to tell. One woman with a urostomy discusses her trip to Florida. She was the only person in her sleeping car that did not have to make the trip to the bathroom.

Thursday, November 25, 1999

Today is Thanksgiving Day. I have much to be thankful about. We visit my son and daughter-in-law. The whole family is there, my son's two boys and his daughter, and my daughter with her husband and their three girls. The turkey, potatoes, cranberry sauce and other trimmings are great. It is good to be alive.

Sunday, December 12, 1999

Today is beautiful. The sun is shining. It is sixty degrees. I go for a two-mile walk and inhale the fresh air, expanding my lungs. I feel great. My weight is now 145. I have gained ten pounds since coming home from the hospital. My life is returning to normal. I have survived cancer and expect to see the arrival of the new millennium, the year 2000, within a few weeks.

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