

## John Ely

John Ely was one of the first people I met online when I began searching for information in 1998 after my sister Maureen was diagnosed with bladder cancer. John and my sister live in the same town in NJ. We met on a few occasions and he was a wonderful, caring and sweet person. He was always there for people both online and offline, he was a pioneer for our group, being one of the first ones to undergo bladder removal. Unfortunately he suffered a recurrence in his liver and lymph nodes in May of 2004.

John was brave and kind, as well as a generous soul; he will not be forgotten. Please read his contribution to WebCafe, which is below his obituary, underneath the photo.

Wendy Sheridan

Wendy Sheridan and John Ely "do lunch" in Asbury Park, New Jersey

Deforest John Ely, 49

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DEFOREST JOHN ELY, 49, of BRICK, died Monday, Aug. 9, at home after a courageous battle with cancer. He owned and operated the Ely Funeral Home in Neptune for the past five years. He was born in Long Branch and lived in Asbury Park and Neptune before moving to Brick four years ago. He was a graduate of Neptune High School and attended Brookdale and Monmouth College. He was a graduate of the Mercer County College of Mortuary Science Program. He was a licensed funeral director associated with his father for many years operating the Ely Funeral Home. He was a member and former captain of the Hamilton First Aid Squad and an exempt member and former chief of the Hamilton Fire Company. He was a member of the Monmouth & Ocean Funeral Directors Association, the Asbury Park Kiwanis Club, a former member of the Shark River Hills Yacht Club and a member of the Shore Acres Yacht Club.

Surviving are his wife of 18 years, Kimberle Horning Ely; three sons, Robert William Wyckoff Ely of Brick, John Robert Ely and his wife, Tracy of South Toms River, and Michael J. Ely and his wife, Michelle, of Beachwood; his daughter, Katherine E. Ely of South Toms River; a grandson, John Robert Ely of South Toms River; his parents, Howard and Patricia Ely of Neptune; his grandparents, Charles and Ruth Davison of Hightstown; two sisters and brothers-in-law, Cynthia and Kenneth Dellett of Saddle Bunch Key, Fla., and Linda and Douglas Durham of Houston; and several nieces and nephews.

John's Story

Cystectomy-Indiana pouch

Hi everyone, I underwent a radical Cysto-Prostectomy on August 26, '99, at Memorial Sloan Kettering in New York City. I had my bladder replaced by an Indiana Pouch by Dr. Paul Russo. Because I've been able to read

so much about this procedure on these bladder cancer boards, my whole ordeal so far has gone pretty much as I anticipated. Most of the surprises have been on the pleasant side.

Because reading of others experiences has been so helpful to me, I'd like to do the best I can to document my experiences with surgery and recovery. First, I'll give a very brief history of my cancer. I was diagnosed with bladder cancer in early June of 1997. My original tumors were T1 G3 with CIS in my bladder and my prostatic urethra. I had a 6 week regimen of BCG which was completed Christmas Eve 1997. Over the next year and a half, all biopsies and cysto's were clean. However, for the whole year and a half, I exhibited positive cytology. In mid July during a 4 month cysto, a small papillary tumor was observed in my prostatic urethra. Biopsies after a TUR the next week showed that it had invaded into the prostate. Because my cancer had gone invasive, the surgery I've just completed seemed like the best option for me.

On August 25, I had to prepare my bowels for the big event, so early in the morning I started drinking a concoction called "GoLytyl". After drinking the prescribed gallon, you "GoFast" and "GoAlot". In the afternoon I took several antibiotics which I understand are also a part of bowel prep, followed by a Fleets Enema in the evening. I had started the mandatory clear liquid diet the day before and continued it on this day. And of course, no food or drink after midnight.

On the 26th, I checked into the hospital at 9:15 AM and went through the requisite paperwork and then on to the pre-op ward to wait. I think I went into the OR around 11:30 AM. My surgery lasted approximately 8 hours. As I started to wake up in the recovery room, I think the first thing I remember feeling for was whether or not I had an NG tube down my nose. To my great relief, they took it out before I woke up. I had a morphine drip right from the start with the ability to give myself and extra dose as needed. I don't ever remember being in any terrible pain. It was always manageable. I was taken to my hospital room about 11:30 that evening. I also had an inflatable splint on each lower leg. These splints inflated and deflated every minute or so. This was to prevent blood clots from forming and causing a pulmonary

embolism. After a day or so, these became rather uncomfortable. I only had to wear them at night and I was able to do away with them after two or three night.

My surgeons' standard procedure is to place the entrance to the Indiana pouch in one's bellybutton. This suited me just fine. I didn't see any point in having any more holes than necessary in my gut. I came out of surgery with five tubes sticking out of me. Three of them, 2 stents (approx 1/16" each) and one small catheter (18 Fr ) came out of my bellybutton, and the fourth thru my belly about 5 inches below and 3 inches to the right of my bellybutton, and the fifth, a catheter in my penis (this one was removed after a day or so).

7:30 the next morning, I drug myself out of bed to start walking laps around the ward. All of the reading I've done says walking is the most important thing, so I forced myself to walk four or five times a day right from the start. One unpleasant side effect that I didn't anticipate was the severe numbness in my thumb and two fingers on my right hand and the same on the whole inside of my left leg from my thigh to my lower calf. This made getting out of bed and then walking kind of a unique experience. I was assured that the numbness would pass. It did, but took three or four days.

I was allowed nothing by mouth, not even an ice chip until I swore that I had passed some gas. After about three days I was allowed to start taking a clear liquid diet (starting with ice chips and culminating with Jello and beef or chicken bullion). Getting on the liquid diet allowed me to be weaned from the morphine. I can't explain why, but I just didn't like the general feeling of being on morphine. Ultimately I was allowed to take 2 Tylenol #3 as needed. I tried not to take any more than I really needed because from previous experience, I know codeine can cause constipation. While on the liquid diet, I developed periodic nauseousness and heart burn. About 1:30 one morning I had a pretty good bout of vomiting.....Thought I was gonna die or at least rip out all of my stitches. I finally convinced the DR that the Jello and beef bullion was causing my nauseousness. Finally, real food.

Getting back to a normal diet allowed for the removal of the stents (the stents drained urine directly from my kidneys to an external collection bag bypassing my new indiana pouch altogether). The first one was removed about six in the morning, and the second that evening. It was a painless procedure, but it was a slightly strange sensation.

About this time the doctor informed me that my lymph nodes were negative and ironically, my bladder was cancer free...Because the cancer invaded my prostate and my age (44), I will go through a course of Chemo.

The next morning I was taught how to start irrigating my new pouch. Essentially, four times a day I squirt a medium sized turkey baster full of normal saline into each of my two remaining catheters and try to draw some of it back out. It's painless. On Friday, Sept 4, I had an IVP to make sure everything was okay in my pouch and that all of the connections were intact. Once the IVP was read and it was determined that everything was OK, I was allowed to be released from the hospital the next morning (Saturday, the 10th day of my hospitalization).

Today is Saturday, Sept 11, I've been home for a week now. So far I've only had to use pain pills very occasionally. The last 3 or 4 days I've started to extend my walking, and the last couple of days, I've been able to go into the office for a few hours to do some paper work. At this point, the only aggravation is the occasional leakage around my belly button. Since my pouch is designed to be continent, still having a tube there allows for the leakage.

All in all, my main complaints while in the hospital were gas and lack of sleep (I can't sleep on my back!!!).

I go back to the hospital on Tuesday, Sept 21 to have a "Pouch Study" done (X-Rays with contrast to make sure the pouch is functioning OK). If all is well, they will remove the catheter from my bellybutton and teach me to catheterize myself. I believe at that time, the other catheter will be plugged and used for emergencies. The next week, the remaining tube should be removed.

Today is Sept 18, I thought I caused myself a major setback on Thursday evening. While removing some gauze from around the catheter, I pulled a little too hard. It became obvious that I had pulled the end of the catheter out of my new pouch because when I tried to irrigate, I could feel the saline going in places it shouldn't have been going.

Sooooo, I called the uro on call at the hospital and he instructed me to come into the hospital the next day. On Friday my wife, my son and I caught the 7:44 train from Bay Head to NY and we were at MSK by 10:15 dreading how they could possibly fix the damage I might have caused myself. I even thought that they might have to cut me open to put it back in. Well, thank God, Dr. Russo came in, yanked the old one out and slid a new one in. It took all of two minutes. The pleasant surprise came when he decided to remove the catheter from my belly button before my pouch study on Tuesday. Whenever I end up with one less tube, I feel that much better.

Update, March, 2001

It is now St. Patrick's day 2001 and I kinda left my story of a year and a

half ago hanging, so I thought I should fill in the blanks. Of course I

ultimately got all of my tubes removed and my new internal pouch started working as designed. As I mentioned earlier, I chose to proceed with a trial of chemotherapy at MSK. Even though my lymph nodes were negative, my surgeon, Dr. Paul Russo encouraged me to participate because it seemed that they were achieving good results.

Dr. Dean Bajorin, also of MSK was the doctor in charge of the protocol I

would undergo. Luckily, my local oncologist who was a friend of Dr.

Bajorin's talked him into letting me take my chemo down here at home. I

will always be eternally grateful for this. Even though the chemo was tolerable, I had my moments, and it was just nice to be right down the street from home.

Therapy was scheduled to begin in October, about 6 weeks after my surgery. Unfortunately, a few days before I was to have my port installed, I came down with a big-time urinary tract infection. It hit me like a ton of bricks. My temp spiked to 105 degrees and landed me in the hospital for 7 days. They put ice packs in places most men would cringe at. After recovering from the infection, I had my port installed and began my chemo in November of '99. My chemo was a high dose sequential instillation of Adriamycin, and Gemzar, given one after the other on the same day every two weeks for five weeks, followed by Taxol and Cisplatin every two weeks for four weeks. The Cisplatin was given over a three day period during this part of the chemo.

My chemo ended just a year ago. During the chemo I developed several other lesser urinary tract infections, but they were nipped in the bud by the antibiotic "Cipro". Finally, I just remained on the Cipro for the duration

of the chemo and everything went well from there. The chemo itself was

hard, but not that hard. The picture of Wendy and I having lunch in Asbury Park, NJ (below) was just before chemo and just after a pre-emptive crew cut. Not long after starting the chemo, I did lose all of my hair. I was kinda hoping for the Kojak look, but unfortunately, I ended up looking like Uncle Fester.....

I am a baby when it comes to throwing up, but fortunately I only threw up

once, and that was after I ate a Whopper at Burger King after a chemo session. Who knew..... The drugs I was given to suppress nausea worked very well. I did get nauseous sometimes, but it was tolerable. I usually felt OK the day after chemo, but 2nd and 3rd day after chemo I felt like crap. I didn't miss too much work time during this, but it wasn't always easy. Worse than nausea, was constipation. I learned to take stool softeners before chemo and for a couple of days after, and this helped somewhat. I also had to self inject Neupogen the 3rd thru the 8th day after chemo to bring up my blood counts. During chemo, I had some bizarre nightmares. I haven't had any since. It took several months to get my strength and stamina back, but it does come back.

Since Chemo ended a year ago, I've had several minor Urinary Tract

Infections none of which caused me any problems. My life has returned to 100 % normal. I do everything I did before. I live on Barnegat Bay in NJ and spend all summer in the water with my son and bouncing around on a jet ski. I don't use sterile technique in the handling of my catheters and the actual catheterizing of my bladder. I just try to be sensibly clean, and so far, so good. I consider myself 99.5 % continent at this point. If I don't drink too much late at night, I can usually last through the night with out

leaking. I do sleep on a "Wee Wee" pad that my wife "borrowed" from MSK, and if I have an accident which happens every few weeks, it's no big deal. During the day, I don't particularly time myself, I just sorta go when I think I should, and that system works well for me. This insidious disease may take my life, but I'm not gonna let it ruin my life.