URINE GOOD HANDS

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Sponsored by:

Shandra Wilson, MD
From Patient to Patient:

Advice and Encouragement for those needing cystectomies and urinary diversion

Note: Each excerpt is written by a patient who received a cystectomy due to bladder cancer. These patients have received a variety of urinary diversions. Each patient has made contributions on their own regard to help future patients that will undergo this operation.

Each patient has provided information on their own behalf and of their own volition. HIPAA documentation has been complied and signed by each patient.
Dear wonderful, interesting person who has recently been transformed into a patient (how crazy is that?!):

Over the past several decades and based on my experience of watching patients go through this surgery, here are my few words about getting through bladder cancer.

To start, thank you for considering receiving your care with our team at the University of Colorado. We have seen many patients go through bladder cancer surgery and recognize that you are going through a difficult time. We greatly appreciate your trust as we partner to help you get through this.

I trained with Dr. Skinner at the University of Southern California where they specialized in bladder cancer, and it is my area of focus at the University of Colorado. I read and write a lot of papers and go to a lot of meetings about bladder cancer. If you have seen my videos, you have an idea about the statistical outcomes from bladder cancer. (Videos can be found by visiting: http://www.ucdenver.edu/academics/colleges/medicalschool/departments/surgery/divisions/urology/Pages/Welcome.aspx and clicking on the Surviving Bladder Cancer link at the bottom of the left-hand column). This letter is not about statistics but rather a short list of things I have seen that seems to make things easier as you go through this major surgery. There are also some handouts available on www.wilsoncancersurgery.org.

First, think about narcotic pain medications. They seem so wonderful and are powerful at decreasing pain. The problem is they can also wreak havoc on your gastrointestinal (digestive) system, your nervous system, and even your breathing. My advice: use narcotic pain medications when you need them. We don’t want you to be in pain! But if you are resting peacefully and the pain is tolerable or manageable with a non-narcotic medication, the less narcotic you use, the better off you will be!

Second, you have most likely spent your life helping others improve their lives. These people probably want to help you now. This might be the first time you have ever felt so vulnerable. You might feel like being alone as you recover. As you go through this process and recovery, you might feel something quite negative or as though you have “failed” by needing some help. These feelings are normal and yet all patients will need some help to get through this experience. Make sure you get the help you need – whether people offer or you ask for a hand – from close family, friends, or even professional facilities designed to help patients recover from major surgery. This is one of the biggest surgeries any patient can undergo. Get all the help you can as you recover! Nutritionists are great, physical therapists (especially ones that focus on bladder training are wonderful) and your local Urologist or we can help with sexual function if that is an issue after surgery.

Thirdly, all the “foreign tubes” that are put in during surgery are there for a reason. Please try to protect them and keep them from coming out. Your life will be harder if tubes are dislodged and come out earlier than anticipated.
I believe in following guidelines that are created from analyzing what works. I believe that in most cases chemotherapy followed by surgery is first-line therapy, but in some situations radiation or skipping the chemotherapy is better. In my practice, I love having you as a partner to help us figure out what is best for you, but I feel like by tending to prescribe care that gives the best results, we end up with the highest number of survivors. When I first started at the University of Colorado Hospital 13 years ago, the survival from invasive bladder cancer was 50%. It is now over 80% at our center for everyone that undergoes surgery and much higher for patients who have little disease after chemo and then surgery. Being proactive, as elementary as that sounds, still pays off.

I’m hoping this book gives helps with some information, but don’t forget to contact us when you need help. The on-call staff answers calls on nights and weekends from 720-848-0000. Our nurses answer questions during the day from 720-848-0170, and I can be reached, as well as my scheduling staff and PA through MyHealthConnection, the electronic portal they talked to you about most likely when they scheduled your first appointment.

Lastly, although this will not be possible every day, and noting that I have never made it through this surgery, I have found that a few personality traits tend to help as you work through this. The traits I would recommend trying to rally through this procedure and recovery include determination, realistic optimism, patience, and a "big picture" focus. Determination to get through this, even when things are hard, really makes a difference in your getting up and recovering well. Realistic optimism can help you focus on the fact that, although you have been diagnosed with an aggressive cancer, cure is not only possible, but probable in most cases. You will need patience to get through this operation. I just read a paper that mentioned 40% of one hospital’s patients needed a repeat operation after surgery. At our hospital, it is less than 5%, but if you are in that 5%, you will need patience. If you don’t have it now, you will develop it. Even if you don’t need any more operations, training a new bladder, learning to use stoma appliances, and having intestines that function normally are all things that require patience. Finally, focusing on the big picture of what you are accomplishing and how much better you are today rather than that day you first heard those words “you have cancer” can hopefully help you get through even the darkest of days.

That is my advice in a nutshell. Remember, "The best revenge is living well!" Go in, get this done, recover, and then go THRIVE! Show cancer it only made you stronger and better than you were before!

Warm Regards,

Shandra Wilson, MD, FACS
Associate Professor
University of Colorado Health
I am two and a half years out since my orthotropic neobladder. After three returns of an aggressive bladder tumor, and two treatments, I decided to go with Dr. Wilson’s advice to go through the surgery… Big decision, but I wanted to live.

I recovered quickly, and Dr. Wilson wanted to release me after 4 nights…I told her they would have to bring security in to get me out, and that I needed the extra two nights. The most difficult part of being in the hospital was getting my bowel movements back in order because of the pain pills and surgery. That was worse than the surgical pain. It took about 6 days to get my bowels going, and I stopped the pain pills after 4 days. The cramping was worse than the surgical pain, and it took another week to return to normal. I recovered nicely, and started walking in my neighborhood. Within 4 weeks I felt well enough to walk 3 miles daily. I had a visiting nurse for the first 4 weeks, which was wonderful. She was positive, and it is important to get one that has experience with patients with this type of surgery. It was very reassuring, and it is difficult for your loved ones to worry about the entire pre- and post-surgery.

By 6 weeks, I was kicking and fishing in my float tube, and hiking in the mountains. After 3 months, I was still incontinent and unable to have an erection. I went to physical therapy, which was a definite value for pelvic exercises, and continue with these and Kegels. I was still incontinent. I was really unable to totally train my new bladder. Because there are no sphincters, and the neo bladder is made up of small intestine, it is not a muscle, so it lets gravity take over, and at night you just release…I needed to get butt pads (Prevails) and I have decided not to get slings or artificial sphincters put in as I just didn’t want anymore surgeries…I am down to 4 depends a day…two of those are during the night and I have to change it after about 3-4 hours into my sleep. I am totally healed up. I hike up and down the mountains like I always did, kick in my float tube while fishing, and cross country ski, etc.

Psychologically, I have dealt with the depends, and have traveled to Africa for a month. I traveled with about 120 depends and 28 prevail takes up pretty much one duffle bag. I was still unable to have an erection, and Cialis didn’t help. Nerve damage is the explanation. A manual pump didn’t help, and I didn’t want surgery to put in a penile pump.

What works like a charm is I self-inject trimix, which hardly hurts, into the base of the penis, and Woolaa, an erection in about 10 minutes…I felt so much better psychologically. It is the concept that is painful, but the injection is nothing. Happy to answer any questions on my experiences, you can get my email. Oh yes, cancer free and never needed any chemo!

Erik Staub
Email: erikstaub@gmail.com
My name is Eric Whyte.

My situation will be somewhat different from many, as I have had a number of surgeries in the past (though none for cancer,) and also have a medical background. Just retired as a psychiatrist for the VA. However, I think there are some very common experiences among all of us who have gone through this. So, here, in no particular order of importance are some thoughts:

I was 64 years old when I went through surgery for bladder cancer in May, 2016, removing both my bladder and prostate gland. I have a urostomy, so collect my urine in a bag that is attached to my side. My story may be different than some people, as I have had a number of surgeries in the past (although none for cancer) and I have a medical background, so I understand some of the medical jargon more than the average person, and did not have much anxiety prior to surgery.

Getting started: Dr. Wilson provides a number of her own video presentations about urologic cancer, surgery, alternative treatments, diet and rehab. It is very much worth the time to watch these, and have key family members or friends watch them with you. Cancer is serious business, but is not a death sentence, so learning what you can about it (rather than just reading statistics) makes it less of a mystery.

I wish that I had taken more time to do some physical therapy to strengthen my legs and abdominal muscles and to practice relaxation techniques BEFORE the surgery, as I think that would help with recovery down the line.

Bring and keep a list of your daily medications at home. Then after surgery you can make sure you are getting meds you need, or if there is a specific reason why the docs don't want you taking one of you usually take. Sometimes things get lost in the records.

When you go in the day of surgery, hopefully you will have a friend or a family member with you while you are waiting, as it often takes two hours between the time the nurse puts in an IV and the time you actually go to surgery. I would advise having just one or two people with you, and people who are interactive, and not sitting there fretting. You could bring in some music or relaxing reading. Before going into the OR, the nurse and/or anesthesia person will give you something to relax you. For me, that means I usually fall asleep before they even get me into the OR.

After surgery, when they get you to your room, you will be sore - there's no way around that, but should be able to find a position to lie in that is more comfortable. I always find that holding a pillow over the surgical site helps contain the discomfort. Carefully read and learn what the 10-point pain scale is and what each level really means. Do not make your pain scale go just from 9-11 (there is no "11,")) as that makes it impossible for your nurse and doctors to really see what effect pain management is having. On the other hand, my wife after her surgery turned the scale into a 20-point scale, as she could not commit to just one number, so she was always a "4 1/2" or "6 1/2" etc. That is okay. It is also helpful to let them know that you may be at a 2-3 when lying in a comfortable position, but it goes to 6 when you move.

There is a tendency to find a position that at least approximates comfort, and then not to want to move ever again. There is a kind of inertia that can set in. However, staying in one position all the time can lead to higher risk of bed sores, blood clots, and greater anxiety about pushing yourself to be more active, etc. Consequently, being still for a period of time is good, but it is
important (with the help of a nurse or a nursing assistant) to challenge yourself to do some moving, sitting at the edge of the bed, sitting on a chair. You will find that knowing what the pain feels like makes you more willing to carry on.

No one likes being in the hospital. No one gets much sleep in the hospital. The metered IV infusion pumps always will make an ear-splitting warning noise at some point. My mother hated being in the hospital and would let everyone know that. "Hating being in the hospital" is a waste of energy, so it is worth taking the time to make the best of it. I have become somewhat adept at staying "half asleep" when people come in the middle of the night for vital signs or a blood draw. This is the one time I am not trying to make conversation.

Figuring out how many visitors you can handle and for how long is important. Family and friends always feel it is important for them to be there with you, but if it tires you out or you find yourself longing for some peace and quiet, you should gently let folks know that you are better at tolerating short visits. This is obviously a personal preference, and not everyone will feel that way.

Speaking of nurses: I always make a point of trying to talk with the nurse and nursing assistant, asking them about themselves, their work, etc. They are so busy that they will not be able to sit for 15 minutes talking about this stuff, but there are brief times when they are hanging an IV bag, doing vital signs, or helping you go for a walk, that you can find a little bit about them, and tell them about yourself. This accomplishes two important things: it builds rapport with the people taking care of you, but also reinforces that even though you are a patient at the present time, you are an intelligent, interested person, and not a half-demented invalid (and not just "room number 7415."). There is a tendency for caregivers to unconsciously treat patients (especially us older folks) as a little grandma or grandpa, so it helps to let them have a way of seeing that you are a lot more than just a patient.

Speaking of nurses (2): Every time a nurse or nursing assistant came into my room, they were paged at least once or twice during the short time they were in there. That illustrates how busy they are, and how ill a number of patients are on the ward, and this is happening to them throughout a 12-hour shift. Consequently, they cannot always come as quickly as we might wish, although I have found UCH nurses and NAs to be quite responsive. Most wards are happy to show a family member where they can get your ice water or some Splenda for your tea. That eliminates one of the frequent calls they get. HOWEVER, this should not make you hesitant to push the nurse button if you need something. If you give the person answering your call a true sense of how urgent the need is, that helps. Consequently, if you can tell that you are going to need the bathroom in the next 10 minutes, page now, rather than waiting until disaster is imminent.

Speaking of going to the bathroom… and other previously private matters: You are having urological surgery, so by definition, caregivers are going to be viewing, prodding and mashing about in some personally sensitive areas. It is best, if possible, to understand this and go with the flow. Staff are very experienced at looking at these surgical scars and I don't think anyone's private parts mean any different than looking at your elbow. Of course, you should ask for adequate cover if you are going out onto the ward, or sitting with visitors. Otherwise, my motto is: forget about physical modesty, but maintain personal dignity. Don't apologize for being chubby (like me) or perceived signs of weak character. You have had the courage to go through cancer therapy, and maybe had to make significant lifestyle changes. Be proud of yourself.
A number of different doctors and nurse practitioners will be coming by to see you. It is okay, and probably smart, to try to write down doctors’ names or ask for a card, so that you have a way of referring to that doctor when one of them says one thing, and another doctor seems to be saying something different. UCH is a teaching hospital, and one of the best. I always ask medical students or interns in the group of docs if they want to take a look or do a brief exam of your surgical wound. After all, these are the people who will be taking care of us when we are 84 years old! However, you certainly have the right to ask only the lead doc to examine you.

You might have some kind of physical and/or occupational therapy introduced while you are in the hospital. It is worth doing the exercises and sticking with them. I have not been as adherent as I should have been, so physical recovery has taken longer than it needed to.

Discharge planning usually starts out as if things are being well-organized, but then sometimes the timing of things escalate and suddenly you find that you are being discharged tonight rather than tomorrow. There is a discharge coordinator, and they seem to do their job well. However, make sure you have your questions answered regarding follow-up, home health care (if indicated), having enough medication, if there are medications that you should no longer be taking, etc. The nurse will sit down with you and a family member or friend to go through discharged instructions, so don't be afraid to ask something you might be uncertain about.
I love Dr. Wilson and truly love the surgeon. This surgery (using the colon as a bladder) can save someone’s life. However, there are so many downsides when you get through recovery.

It is hideous. I still have problems with my colon after the surgery. From what I understand from my investigations, anytime you cut the colon, it disrupts the memory. I still need to talk to her what I think I consider contractions when you have when you have colon problems or with constipation. I have terrible things with the bladder that I don’t know what the hell this is about. The memory of the colon has got to relate to the brain sensors, and now the bladder is related to colon sensors, and causes contractors.

I need to cath every day of my life 5 times or more, but it causes UTIs and I have blood in my urine. There are a lot of downsides, but it saves my life.

Sex life is gone. Cannot even sleep without wearing a diaper since the sphincter is gone. All the chemo that you have to go through prior to surgery almost killed me. I almost would never go through with it again. I would give my life to god and it is the worst surgery ever. I had no idea how horrendous this is. No one would tell me it was this long or have this long of a recovery. They take apart all your organs and have to put it back together.

I love Shandra, I really do. They need more back up and more details. I don't know if it is up to her or her staff, but think the team was phenomenal and was very good. And the staff. But the guys coming in to checking in and they were great and the nurses were great. The hospital was absolutely phenomenal. All my doctors at the hospital were great. I won’t go anywhere else. I would recommend anyone with doubts need to get a second opinion from UCH. I do that constantly. I think going into this surgery, people need to be more informed about the aftermath.

There is a LOT of recovery problems that could be life-long. It destroyed my sexual life and my sphincter and all my constipation and diarrhea.

Frederick M. Bowers
First of all, let me tell you both what a wonderful thing this project is and thank you for doing it! Thank you for your compassion. I would think that the one outcome for your future patients is for them to know they are not alone. Others have gone through the surgery and recovery, and it isn't easy, but it can be done!

I had little time to think about the surgery. The tumor was discovered in June, removed in July, and the bladder was removed in August. Thankfully, I was a candidate for a Neo-bladder. I haven't had a moments problem since the operation. I have no trouble voiding. The only real problem is the incontinence at night. I wear the appropriate protection, a Depend and pad, and get a good night’s sleep.

Just after the operation and while still in the Hospital, I developed a sensitivity to cold. I still have that sensitivity to cold now, 5 years later. I also remember being somewhat depressed and I had no patience with my family. Looking back, I certainly could have handled myself better. I think if future patients are alerted that the body will go through a great trauma, tubes will be hanging out, and they feel just plain crummy, perhaps they will better be equipped to handle the moodiness.

I would be happy to talk to anyone undergoing the surgery. I had the same opportunity before my surgery and that was a great help. I would also be happy to answer any questions you may have.

Jim Fairley
Email: LMAXJFAIR@comcast.net
Here are some of my thoughts:

- I was encouraged by the caring professionalism of all of the treatment providers throughout the entire process. This was a huge boost to my maintaining a positive attitude.

- Early in the treatment process I was given contact information for other people who had their bladders removed. I found their input and advice to be very helpful.

- I received chemotherapy prior to surgery. I found that my apprehension about chemo was unfounded. Dr. Flaig prescribed extremely effective anti-nausea medication, both prior to and during infusion. I experienced no ill effects from chemo and drove myself to and from each treatment. I did experience “chemo brain” (spacey, inability to concentrate) near the end of treatment, but that soon went away.

- Post-surgery pain was well-managed. I was not unduly uncomfortable.

- Recovery seemed at the time to be slow, but this is intensive surgery (I received a neobladder). In retrospect, it went well. I had the surgery in September and was able to resume my activities as an accountant prior to tax season.

- It is important to have someone at home to assist during recovery. You may need assistance with both medical and nonmedical activities during this period. You will be on powerful pain medication which may cloud your judgment.

- I am now seven years out from surgery. The neobladder is functioning well and I participate in all normal activities. There are only two minor issues:
  1) I am periodically somewhat incontinent (a little leakage, especially while sleeping).
  2) The neobladder sometimes does not fully empty. While this is minor in my case, it can require periodic self-catheterization if it becomes severe.

In summary, this is an absolutely manageable treatment for bladder cancer with few lasting after-effects.

Mike Frohardt
On Peeing

(with apologies to Krista Tippett)

In 2010, I had a bout of Epstein-Barr Virus (aka mononucleosis), complete with post-viral fatigue. In my quest to fix this fatigue I consulted a natureopath. We discussed my symptoms, and drew some fluids for lab studies. At our next meeting he asked,

“How long have you had blood in your urine?”
“I have never noticed any blood there” I said.
He explained, “It’s there but its microscopic.”

I didn’t bother to explain that I don’t have the skill set, equipment, nor inclination, to study my urine. He told me he can’t say with certainty what’s going on, but I do have an “event” happening in my urological system. We agree that this is something to monitor closely.

In true male (or Mike) fashion, I blithely ignore that which I cannot see. If it is not visible, it is not a problem. Denial abetted by the absence of visible evidence is a powerful force. But then came the fateful day that the blood revealed itself to me. My attention was now laser-focused. I called my urologist the next business day, reported my symptoms, and got an appointment for the following morning. Doc refers me for a CT scan of kidneys and surrounding vicinity. The results are unremarkable; prostate enlargement (I knew that), bladder diverticuli, evidence of chronic over distention. The next step is a cystoscopy, a medical term for what is actually a cruel and unusual procedure developed by a sadistic photographer (probably female) which involves the insertion of a camera through the urethra into the bladder. Do I need to repeat that for effect? I didn’t think so.

On the morning of the procedure I am prepped by an efficient nurse. My feet are put into stirrups. I don’t make pithy, empathetic remarks about how I’m beginning to appreciate how women feel when visiting their OB/GYNs. The doc comes in and shows me the camera; a long, thin, flexible tube designed to make an uncomfortable procedure as tolerable as possible. But as the insertion process begins, the long thin camera tube morphs into a Canon 35 mm SLR, with strap and an EF 800mm telephoto lens. The type used to photograph close-ups of insects across 300 yards of jungle canopy. As the camera goes in doc points out the sphincter (which looks like the shutter on said 35mm SLR). He said I would feel a “strong need to urinate.” What I felt was a strong urge to get the hell out of there before things got any weirder. The inside of my bladder looks a little like the album cover of the early ‘70’s Zephyr recording “Moonlight Ride” - darkening sky, setting tropical sun silhouetting a lone palm tree. OK, I took a little license there. The tropical reference comes from what I believe the ambient air and water temperatures to be on my pelvic floor. Otherwise my bladder looks like a poorly lit, underpopulated aquarium. The doc points out a growth extending from the bladder wall. He says it looks like a “sea anemone” (yet another tropical reference). I catch only a brief glimpse as he re-positions the camera and I
re-position my gaze. I see something resembling a small fan coral. The doc opines that said growth needs to come out. He says he has an instrument like “a steam-shovel” that can go in and remove the offending growth. I want the growth removed but I have qualms about a dual-tracked vehicle with a long articulating arm that wields a toothed bucket going through my already stretched urethra and re-arranging beach-front property that is my bladder. I do, however, schedule the earliest possible appointment for the procedure; January 22, our 36th wedding anniversary and our daughter’s 32nd birthday. Comments are made about the lengths I take to avoid taking my wife out to dinner. I point out that more money will be spent on this anniversary dinner than all previous anniversaries combined. This does little to lighten the overall mood.

But before the day of the removal procedure…BOOM, I get very sick. Sepsis septicemia, septic shock, whatever you call it, it is some wickedly bad stuff. It merited an extended weekend stay (Thursday through Monday) in the ICU. While there, they virtually pour fluids in me trying to keep my blood pressure up. True story: I go in weighing a lean, not so mean 194 lbs and I come home weighing 214 lbs. I look and feel like a water filled off-spring of the Pillsbury Doughboy and the Michelin Man (gender doesn’t matter in my metaphor, or is it an analogy?).

**Part II: The Signal and the Noise, or How You Know When You Need to Go and How You Know When You’re Done (with apologies to Nate Silver)**

During our earliest months of life, we are blissfully unaware of any signal indicating that we need to pee and any noise that indicates a successful emptying of our bladder. It is just internal function. The responsible adults in our environment take care of the necessary clean up. At first, they think it’s cute. Eventually these adults grow tired of the clean-up process and decide that we need to learn how to recognize the signal and the noise ourselves. This task is accomplished through a series of steps: our wetness is pointed out to us and we are introduced to “the potty.” After a series of successive approximations, we learn to recognize the signal and respond appropriately by making our little noise in the loo. From then on, we are on our own. We sense the signal, scan the environment for the nearest facility based on accessibility and cleanliness, and we take care of business. Adult continence is a beautiful thing.

Now, remember my recent homecoming with 20 lbs of fluid on board? Well, that soon produced a signal of epic proportions. It was a signal indicating the confluence of numerous Niagara Falls was ready to be released. I made it to the bathroom and let go as much as humanly possible. The noise produced was that of a lone icicle slowly melting on a cool January afternoon. What was I to do? The signal was now an air raid siren stuck on a monotone high alert but I was unable to unleash the torrents within. In desperation, we call the doc’s office, “C’mon over” they say, “We’ll take care of it.” So, with my signal on so intensely I’m sure others in the vicinity can sense it we make it the docs office where they do an ultrasound of my bladder. They tell me it contains 950 mls of the golden frothy liquid. I know from my ICU stay that the bladder is designed to hold at maximum 400 mls. Remember the old adage of feeling like ten pounds of poop in a five bag? This was literally feeling like ten pounds of pee in a four-pound balloon, or like having the Fort Knox gold repository in a coin purse. The two young female medical assistants insert a catheter into Mr. Really Unhappy and we chat amiably while my bladder drains a full 750 mLs into the urinal. Yep, 750 mLs. Remember that expensive bottle of scotch you covet? That much was drained. I noticed that they didn’t dispose of the said urine and imagine they will show that to their young colleagues; “We got this outta the old guy.” I am so
relieved (pun intended) that I don’t really care what they do. I want to hug them but that would have been awkward as I am exposed with a foreign object extending from said appendage.

As a final gift, these young ladies explain the self-catheterization process and send me home with the necessary equipment. Self-catheterization is a procedure that you really don’t want to learn unless it is absolutely necessary. It was absolutely necessary. It came in very handy for the several days it took me to drain the 20 lbs of fluid from my swollen body. Each time my signal out performed my noise, the catheter went in to help relieve the pressure. When I didn’t want to do it myself, I had the aid of my lovely blond assistant. She deftly inserted the catheter and helped “drain the lizard” as they say. She did this with an air of care and concern, of empathetic competence. But I can’t help but think that she exacted at least a bit of revenge during the process for how I will drastically alter our usual anniversary plans.

The Day of the Procedure: Happy Anniversary

We get up early and I take my second shower with Hibicleanse to ensure cleanliness while Ellen savors a cup of coffee. She even pours a traveler cup to enjoy on the way to the hospital. Although I am strongly tempted by the coffee’s rich aroma I am strictly NPO. I can’t help but think that this is another bit of her sadistic revenge. Once we’re at the hospital I am weighed, vital signs are taken, an IV line is started (this despite having a PICC line in place which was installed while in the ICU), and numerous people ask my name and date of birth. Fortunately, someone had placed a wrist band on me with all the pertinent information so I refer to it frequently and apparently pass the test despite the obvious presence of the cheat-sheet. I did well enough to earn a spot in the O.R. where (I’m told) things went quicker that planned, despite finding another sea anemone attached to my bladder floor. Doc tells Ellen (and later, me) that things went well, everything that needed to come out (cancerous tropical-looking growths) was removed and there is no evidence of any spread.

I’m placed in a private room (in lieu of isolation, which had been considered because of my recent septicemia) and the bladder irrigation process was initiated. This involves the insertion of an extra-large catheter that has three tubes; an in line, an out line, and another line just for good measure, left unused. Huge bags of fluid are hung and my bladder gets a thorough rinsing. I know that more fluid is poured through me than mother nature has provided in the way of precipitation in our fair city for the past two months. The large amounts of fluid and the large-bore catheters mercifully preclude any signal and noise response on my part; it would have been humanly impossible to keep up with that deluge. Our anniversary dinner consists of a shared order of hospital chicken fingers and French fries.

The process of bladder irrigation, and the presence of the large catheter requires frequent checks of the equipment by nursing staff. By this point (after insertions of cameras, surgical equipment, and home, office, and hospital catheterizations) I have completely lost any sense of modesty or propriety, “Sure have a look.” I almost flash the nice lady from housekeeping who only wants to empty the trash and sweep the floor. I worry about becoming an exhibitionist.

With the irrigation process, complete I am sent home the following day with the catheter still in place. A modest size leg bag is taped to my thigh. I wonder if I could pass through a TSA check with more than 3 ounces of liquid, not in a quart bag in my carry-on. Fortunately, I’m not traveling, so this won’t be tested. We are instructed to remove the catheter the next day, “But be
sure to deflate the balloon that keeps it in place before you try to pull it out.” Good advice indeed. Even with the balloon deflated it was an uncomfortable process at best. The amount of blood I passed makes the toilet look like a crime scene.

So now I am without a catheter and my PICC line was been removed. Ellen says I’m “Mike unplugged.” I am already planning something a little less special and a lot more enjoyable for our next anniversary.
Dr. Wilson was a wonderful, caring surgeon for me. I was 11 days in the hospital. The hospital staff was competent, though mechanistic. Sleep was a rare commodity. One nurse offered to massage my feet, and that was great. Perhaps one should consider requesting that. The food was good.

Nothing fully prepares you, but my advice is never be intimidated to ask questions, and as mentioned, foot massages if possible.

Visitors obviously help pass the time and get your mind off the unnatural setting you are in. I had, and I believe anyone should have, confidence in Dr. Wilson.

Jeff Jerebker
I was diagnosed with bladder Cancer in early February of 2006. My symptoms were having to urinate about every 15 minutes, so I thought I just had a UTI and called my PCP for a prescription. He had me come in for a urine test and it showed lots of blood in my urine. He then sent me to the hospital for a CT Scan and called me the next morning and had me come in and confirmed that I had a tumor on my bladder that he was sure it was cancer!! I had the same reaction I think most people had when told they have cancer. Am I going to die? Is it curable? What steps need to be taken? What do I do now? etc.

The first thing my PCP he did was send me to a specialist who did a cystoscopy and a biopsy. Then, my PCP sent me to a chemotherapy specialist for a consultation – this doctor said there was a 50% chance of recovery if I took chemo – and then to a radiologist for a consultation. I then went to University Hospital to consult with a surgeon (who was very rude and had a very high opinion of himself). He just looked at my records and said I needed to have surgery and basically walked out of the room. My husband and I decided to take a chance, so I had chemo and radiation for 6 weeks, another cystoscopy and CT Scan, plus an MRI. We found out there was no improvement.

So, back to University Hospital where we met Dr. Wilson! What a change. We both fell in love with her immediately. She is the most caring, intelligent doctor I've ever had and she worked me in very quickly to have my surgery. She informed me of several things that could happen from the surgery. She knew I hated the thought of having to wear a "bag" but said if at all possible she would make me a neobladder. I can't remember how long the surgery took but bless her, she was able to make me a new bladder! (She said it was the last one she would do on someone who had had radiation!) I did have to wear a bag at home for a couple of weeks after surgery - I don't remember much of that as my daughters took over the task of emptying it and flushing it out. A week or so after I got home I got C-Diff which is a horrible infection that lasted several weeks and basically took my mind off of my surgery!

I had cancer from the first of February through June 6, 2006. Since surgery, when Dr. Wilson took out my bladder and all the lymph nodes surrounding the bladder, I have been cancer free. I know I had some problems later but just can't remember them. I do know I wish I'd never had chemo, because a couple of years later I found out the chemo that was given to me damaged my kidneys and I am now stage 4 Kidney Disease and am on the transplant list!!

Of note, about five years ago my assistant told me he was diagnosed with prostate cancer and had decided he wasn't going to do anything about it. I called Dr. Wilson and asked her if she handled prostate patients. She had me tell him to call her nurse and make an appointment. She worked him in right away and two weeks later he had surgery - everything went great and he and his wife also think the world of her!

I don't know what information to give new patients as far as their surgery goes, except to let them know that I believe Dr. Wilson is the best surgeon and I wouldn't trust anyone else!

Sorry to ramble on but it's been 9 1/2 years since my surgery.

Virginia Howe-Reseutek
2015 was our lost year. After the initial shock of our cancer diagnosis, I spent the summer on chemotherapy in Fort Collins, our home. This was a prelude to surgery scheduled for some time in the fall. I worked as much as I could while reading everything we could get our hands on and meeting with others who had walked this road before me. That was a double-edged sword, as I later learned everyone's journey is very different. I tried not to think about the upcoming surgery because it brought up too many fears. After my last chemo treatment, we organized a trip to New York City to seek a second opinion. The trip was in late September and we stayed in Manhattan, near Sloan Kettering. President Obama was in town, and the United Nations was in session; traffic was terrible. We had dinner downtown with an old friend. The next morning, we caught a cab in the rain and went to see a surgeon who specialized in bladder cancer. We were told he was the best, which seemed to be true because when we arrived early in the morning the hospital waiting room was already full. There were perhaps 40 people from all over the world who’d come to see his team. It was very comforting to have my wife with me in this strange new place. After a couple hours, we visited the doctor. He was very impressive. Although I'm sure my wife remembers many more details than I do, a few of his comments resonated. First, he concurred with the recommendations from Dr. Shandra Wilson and her team back in Colorado. I had bladder cancer and needed to get the bladder and prostate out. Chemo had been a good idea. Getting a neobladder was a great option for me, due to my age (late 50’s) and fitness level. He also said that although I looked great post-chemo, time was ticking and I needed to schedule the surgery soon, so the surgery would be curative. He stated for such a unique type of cancer surgery, studies report that patients using doctors and hospitals specializing in this type of surgery do much better. He could fit me into his schedule, but I’d need to commit soon. I’d also need to find housing for at least month post op in New York City. It was a lot to absorb.

We spent a week in Virginia before coming home and decided to take his advice and to get the surgery scheduled soon. We also agreed it was important to use a team specializing in this type of cancer, in other words the very best. When we got home we called Dr. Shandra Wilson at UCH and told her we were ready. The decision felt right as we could be close to home and knew we would be working with a great team. In October 2015, I had the surgery and it went according to plan. There were, of course, challenges, which we faced day by day. This is where I learned that everyone's journey is different. Some of the information I gleaned pre-surgery was just not relevant, some was spot on. After a week I was home, and after another week I was slowly up and about. After a couple weeks, I could slowly walk around the block with my daughter-in-law, arm in arm. Soon I was back to working part-time and then full-time. The body has an amazing ability to cure itself, especially with great care and a positive support network. It’s now been just over a year, post-surgery, and I am doing the same things I did before. In October I worked in Costa Rica, giving a presentation to a group of my peers, and then met with the Minister of the Environment. On the one-year anniversary of the surgery Sue and I celebrated by floating Costa Rica's Pacuare River, one of the world's most scenic rivers. In short, 2016 was not a lost year for us and I am thankful to everyone who helped me, and my family, down this road!

Sincerely,

Rick and Sue Harness
I remember how I felt when the Doctor informed me that I had bladder cancer. There were many questions that he could not answer at that time so I left still trying to process the information. During the following weeks, I read about the cancer and started to think about the possibilities involved depending on the severity of progression. I did not become an expert in the disease because until I knew more about my own cancer I did not want to dwell on any possible outcome that may or may not happen. So, I waited for the surgery to determine the extent of my cancer.

After the initial surgery, I was told that it was stage one cancer and the treatment that would be involved. This was very good news, but the surgeon mentioned that he could not be certain that he got all the cancer but was reluctant to go in again due to the location of the tumor and the possibility of kidney failure. My wife and I decided that our best option was a second surgery to verify that the original diagnosis was correct. This proved to be a very wise decision because the second operation determined that I had at least stage two cancer which required removal of my bladder. We were referred to Dr. Wilson and the Colorado University Hospital in Denver.

My wife and I both believed that surgery was our best option to combat the spread of the disease. In the meantime, I did have kidney failure and spent ten days in the hospital to get that taken care of so that I could get healthy enough for the big surgery in Denver. That surgery took place on August the 4th, 2016. The result of that surgery determined that I had stage four cancer and would require further treatment with chemotherapy.

The recovery from this last surgery was long and required an 11-day stay in the hospital before I was released. I won’t get into details on the specifics of what I went through, but it was a very long four-month period between my initial diagnosis and the final surgery.

I mention all of this so that you may understand that there are many things that are involved in treating bladder cancer and many things that can go wrong and cause stress and anxiety. Coupled that with the possibility of death-- you can imagine how that effects your mental and physical health. How did I survive all of this and continue surviving not knowing what the final result will be is what I would like to address in the rest of this letter.

First and foremost. The thing that allowed me to stay positive and hopeful is my unwavering belief in God and Jesus Christ. It is this belief and certainty of what will happen, no matter whether I live or die, that gave me the strength to accept any outcome and still remain relatively stress free and happy throughout the ordeal.

The ordeal did indeed make me examine my standing with God and have many talks with Him, but I also understood that no matter what, He had my best interests in mind. Romans 8:28 has always been a verse that has sustained me throughout my life and continues through this ordeal also. It basically says that if you belong to God then He makes all things work for your good. I have always believed this to be true and continue to do so. Without getting involved in a lengthy theological discussion I basically believe that nothing in my life happens without God’s approval. I basically trust Him no matter what. This is called faith to most, but it is based upon my certainty of this truth.
Did I have some sleepless nights? Yes, but very few that were caused by worrying about what the future holds. Did I examine my life and my relationships? Yes, but with the understanding that it gave me an opportunity to improve them. Did I pray? Without ceasing, trying to understand what God’s purpose through this was.

I guess the most important truth that keeps me going is the understanding that no matter what happens God intends it for my good. I do not fear death and will accept that if necessary. How I view death is finally getting to be with Christ. I can appreciate what the apostle Paul said the Philippian church when he mentioned his own predicament about remaining on earth or his possible death. He said that death was much better than remaining here, but he probably would remain for their benefit.

My only real sadness is leaving those I love behind and having to suffer through my passing. I will remain as long as possible for their benefit so that I can minister to them and alleviate their fears and concerns.

To those who do not have my faith I would say that we all only have a short time on earth and we should do what we can to ensure the happiness of those around us. Think of them more than yourself and feel sorry for them and not yourself. Most important is ask God to show you the truth. That truth has certainly set me free to be happy no matter what my circumstances.

Joe Fabian
The comments and advice I would give are:

1. Although it is a long road to recovery, things will get better. You should be able to do most anything you did before. I am 68 years old and I am back to weightlifting, skiing and scuba diving.

2. If you have incontinence issues or remaining pain issues, get physical therapy from someone with experience dealing with these post-surgery issues. The therapy can be very helpful.

3. Keep doing Kegels, make them part of your daily routine.

4. If you have night time incontinence and self-catheterization is recommended, be open to self-catheterization. It is not as bad as you may think it is.

If I can be of additional assistance, please let me know.

Scott Karas

Email: sherianscott24k@yahoo.com
Not being a GREAT letter writer I hesitated to write this, but what a great way to honor the very doctor that put my life in her hands almost nine years ago. Dr. Wilson and her staff were the best thing that could have happened to me during those difficult and trying times.

Coming from a small town and being told that you have to have your bladder taken out was quite the shock. When I walked into CU Hospital and met Dr. Wilson, this complete calm came over me and I knew she would take care of me. Of course, I was super afraid but she certainly made me feel that I was her only patient and explained everything to me in terms that I could relate to. After getting comfortable coming in for my appointments she was never in a hurry and always had time to sometimes just visit. I think that was the most important quality besides the operation.

As for advice, Dr. Wilson and Pat always let you joke around with them, so you felt as if you and your team could conquer anything. I knew it was very serious but really from day one I always had complete trust in the doctors and nurses. Complete honesty is what I always felt, and I thank them for that.

Today I am cancer free and spending time at the river in my kayak and traveling when we can. The three kids gave us a 50th wedding anniversary party three years ago so things have really gone back to normal. OOPS - forgot about the age thing. That has slowed us down a bit- HA!

If any questions just send me an email, suet@bresnan.net

Much Love,

Donna Sue Thompson
Thank you for caring. I have several comments.

1) The drugs following surgery were brutal. Fever. Throwing up. Miserable. Review prior to surgery if possible.
2) The two-hour trip home was difficult. Need pillows comforters or something to ease the drive.
3) I was told I would be as good as new one year after surgery
   - It took me three years. I am still having difficulty organizing bowel movements and often have too much at one time. This can ruin my plans for the day and leaves me weak.
4) There should be more info about urinating following surgery.
5) Age has slowed me down. I'm working out at a therapy gym for strength and balance. I still use self cath. I still show my little terrier (a new puppy).

Thank you.

Anne Power

I have another addition. Yes, the whole experience was scary. I am not usually fearful and am very active so I think I was a bit in shock. I did have an excellent home nurse.
Hi fellow patients,

I think the hardest aspect of surviving bladder cancer for me was knowing what questions I needed to ask as I plodded through my therapy and eventual operation for bladder removal and rebuild. I looked at the literature and googled the functions, but it is fairly general, so if you have a family member or good friend to help you wade through the info it is helpful. It is very important for you to have someone as your advocate if you end up having the surgeries. I knew that there was a possibility of bladder removal, but I think it helped me not to go to that point in the beginning. I know a number of people, men that have been able to keep going with the treatments. So here is some of my story.

I initially was diagnosed with urinary tract infections. I was told it was common for older women to have these quite often. I had not, but I went along with it for several months. This was from local practitioners- I was not referred to a urologist for several months. Looking back, I should have been more proactive. That, of course, is very individual. My urologist determined that I had a non-invasive carcinoma and referred me to Dr. Wilson at University Hospital-Anschutz. Getting appointments in the beginning is not timely for many specialists, but I did see Dr. Wilson in about six weeks. I was told I could start treatments as soon as medicine was available- that turned out to be two months. I was also able to be put in a trial, in my case, I eventually was taken out of trial. I was given an intravesical treatment for nine weeks. (The drugs were injected into my bladder by catheter). BCG and chemo drug. The last treatment of chemo was very painful and I could only stay with it for about twelve minutes.

In my case, I became incontinent and remained so until my bladder was removed eight months later. In the next eight months I had more chemo treatment and scrapings. I saw my urologist, got medication, I finally got to see University of Colorado’s urologist, I tried physical therapy and finally botox to stop the uncontrolled urine flow. As far as I know, the cancer did not return, but I was told my bladder was shrinking. It had to be removed. I was offered a couple different end results regarding type of urinary operation.

I had radical cystectomy. My bladder was rebuilt and I use catheter via stoma in my belly button, which was my choice. There are other options which include wearing a bag. This is a very serious operation!! Dr. Wilson estimated two weeks in the hospital. This was not the case for me. I was in and out of hospitals for closer to two months. Initially I had a lot of pain and was given heavy narcotics. I was transferred to another hospital to mend. I had abscess and infection, I was transferred back to Anschutz, then sent back to second hospital (I did not like the critical care hospital) I asked to go home and get off the fentanyl patch that I had. The critical care hospital sent me home for home health care. I took off patch not knowing the drug had to be reduced slowly in my system and ended up back at Anschutz for drug help. When I got home, the drugs reduction was awful, I was sick for two months. During that time I saw Dr. Wilson to open the stoma, but before I got to use it, the canal to bladder had filled in with scar tissue. I had home health care for about a month- it started off as “wound care” and continued until the nurse felt I could function alone. I lived mostly alone! But family and friends stayed with me off and on during this time. I didn’t feel like having company most days- although in my case, I think most of that had to do with the drugs. I recommend to anyone, be careful with the drugs/narcotics. I am not sure doctors are really up on the drug regimens/reactions. I had to function for about four months with the supra cubic secondary setup- it worked OK, but was not
what I wanted, I was able to go without the bags most of the time as my bladder was built to hold a lot of fluid. I had lots of leakages and accidents that gradually diminished. The bladder had to be injected every day to remove mucus from the bowels. Some of this information was given to me from Dr. Wilson’s office and some info comes from the nurses and some comes reading. I also took three trips during this time (After the drug withdrawal- car and plane including Germany). When I felt well enough I had the canal procedure done again. I refused the fentanyl and came through that surgery much better. I am not saying it didn’t hurt, I toughed it out, my choice. The temporary catheter placed in my belly button to keep canal open fell out, I couldn’t get it back in, I had to go to local emergency room to get another. (Scary but small stuff).

It all works now. I prefer a more rigid catheter than the noodle one provided by hospital. I flush my bladder two to three times weekly now. I feel pressure at times to relieve myself, but mostly I have to just remember. I still leak on occasion! I had lymph nodes removed during surgery too, although I didn’t pay much attention to that aspect until my left leg swelled up and I now have lymphedema in my left leg. My regular physician was unfamiliar with lymphedema and it took several months to finally get treatment- which I initiated. I was just recently custom fitted garment and compression socks. I think the treatment I get weekly and the stocking are helping get rid of the waste, but I am adjusting my regimen now as I have noticed more bladder leaking since I started the lymphedema treatments. I hope that will diminish.

I am on the road to recovery. I just returned from a cruise. I am doing exercise and plan to start up water aerobics again. I expect to get better. There are upsets, like the leakage, but it will change. I am a positive person, although I will admit the drugs affected my personality, I was inconsolable at times, my friends and family will tell you.

As I started off, having an advocate, in my case, my daughter, was very helpful. I have a woman friend who I can talk to about all of this and went to procedures with me when I was under anesthesia. We are all different, so different things are important to us. I now realize I had questions, just didn’t ask them at times, but I came through it anyway. I am 74 years old and a widow. What’s up next?

Judy Meyer
Dear future cystectomy patient,

The first and best thing about your decision is that you have chosen the absolute best in Urology, Shandra Wilson! She is tops in skills and caring. Now for the bad news –

This surgery will be the toughest thing you have ever taken on; your body will feel as though it has been run over by a truck, assaulted in ways you never knew. When you wake up, you will have tubes and wires attached everywhere and you will be unable to roll over in your hospital bed. The nurses will wake you, when you’re desperate for some sleep, for vitals, injections, blood draws and just to make sure you’re OK. When it’s the last thing you want to do, they will get you out of bed and have you do laps around the hospital to regain your strength. When you are being driven home, every little bump will yield abdominal pain.

Once you’re home, you will need to learn how to adjust to your new mechanics, changing your ostomy bag, attaching a night bag, having a repair kit with you at all times in the event of an inconvenient (they’re all inconvenient!) leak.

Here’s the good news: the food at the hospital is remarkably good and quick. You have taken an important step in saving your own life. And you and your body will adapt to the new routine so that it becomes second nature.

Two things are critically important:

1) Attitude: always approach every step of the way with the idea that your positive attitude is going to beat this. You are a winner and nothing is going to get you down.

2) Support: having the positive support of your partner or spouse is key to getting across the bumps in the road that will necessarily occur.

And remember: every day is a blessing!

*Patient would like to remain anonymous. Please respect their privacy.*
I had this surgery more than ten years ago and the very first thing that comes to mind is I was so anxious to leave the hospital following surgery I left a day too soon. If I had it to do over, I’d stay an additional day.

About five years after the surgery one of the ureters closed because of scar tissue. That created a situation whereby I had ten kidney infections in twelve months. I had to have Dr. Wilson perform a second surgery to move that ureter to a different site on my stoma. I continue to have occasional kidney infections two or three times a year. I now know when I have one and I immediately go on Cipro, an antibiotic that treats urinary tract infections quickly. My primary care physician keeps me supplied with a prescription for Cipro.

I was still working so I took my time in recovery. I went back to work two months following surgery. During that time, I did all the physical therapy recommended exercises. My bedroom in our house is on the second floor. I stayed up there for a week before attempting to navigate the stairs. When I did return to work, I took it easy the first week. When I got tired I went home. It seems I was in the office about four hours the first day. I was able to stay longer each day until I was there for a full eight hours by the end of the week.

My wife was incredibly supportive throughout the entire process. I was a pastor and the whole church was very supportive during my recovery. I have had multiple opportunities to visit with patients of Dr. Wilson before their surgery to discuss the pros and cons of the different surgeries—ileal conduit or not.

I also experienced caring, helpful support from the entire medical staff. I couldn’t have asked Shandra to have been more caring and supportive. I refer to her as my angel whenever I see her.

I was so grateful to have a stoma nurse visit me three or four times in my home soon after surgery. She was able to show me some very helpful hints on caring for the stoma. I have had NO problems at the surgery site. My skin has remained healthy. I did discover an extremely helpful product for catching the urine at night. It is manufactured by Nu-Hope. It is called a travel urine collector. I use it every night whether at home or traveling. I rinse it each morning with white vinegar and water. It is so much easier to clean than a Foley bag. It lasts many months and my insurance pays for it. I have also learned in the past year when I hold the wafer against my skin for twenty-thirty seconds it warms the adhesive enough it will mold more closely to my shape and lasts several days longer than it did when I just pushed the wafer against my abdomen long enough to get it to stick and then attached the pouch to it. I now change the wafer once a week. I change just the pouch in between. Obviously, I use a two-piece system.

I have always felt secure knowing Shandra was only an email away if I needed to ask a question or describe a dilemma. I am also grateful that she and my primary care physician are in contact, should the need arise. I cannot imagine going through this surgery and the recovery with any other surgeon than Dr. Wilson. I am available for conversations either by email or telephone.

Gaylord Hatler
(gayhatler@yahoo.com)
This was a true adventure. A true adventure is one where you hear yourself saying "Lord get me out of this and I promise I'll change my ways."

I was scheduled for four rounds of chemo, with each round being a month long. After the third round, they sent me to Dr. Wilson and we scheduled the surgery.

I was torn between having the surgery or taking my chances. I suspected that I didn't have any cancer left after my other doctor removed the large growth. I suspected that he may have called it a stage 2 just to be on the safe side. I suspected that the doctors that followed, relied on his diagnosis. Dr. Wilson took a look inside and described the scar as "dime-size." She set me up for a Tumor Board. The board concluded that I still needed the full bladder removal.

Funny story about that; Dr. Wilson called me with the good news that the board recommended a partial. As we were discussing the time frame of what to do next, she realized she was looking at the wrong chart. She said "Oh, I have some bad news."

A cousin of mine is an oncology radiologist. After talking to him, I decided to go ahead with the surgery. He described many cases of people who had turned down the surgery, only to return later with spreading cancer.

The surgery went well. Dr. Wilson is an excellent surgeon. I had lots of drains and tubes. The hospital staff handled the disgusting stuff just fine. Dr. Wilson and several others checked on me frequently and answered all my questions. I was told that along with my bladder, my prostate was also removed. I didn't know they were going to do that. I went home after five days. Then I had to do all the disgusting stuff myself. I soon found that I needed to put plastic sheeting on all the carpets and the bed. My wife slept in another room and still does.

It was at this point that I discovered the difference between in-patient and out-patient. In the hospital, as I said, I was well informed and well-tended to. Upon discharge, I was given a number to call if I needed anything. I should have tried that number before I left. There were certainly many questions that couldn't wait till the next business day. At times, I was leaving messages all over the hospital.

Here's one problem I ran into; three of the tubes coming out of my neobladder were tied together with a suture. The suture was stiff and sharp and it was cutting into my leg so I cut it off. Then I saw the purpose of the suture as two of the tubes started coming out. I fixed it with duct tape. I don't ever want another catheter. That was the worst part of the whole adventure.

Here's something else you should pass along; you can attach the bags to your leg instead of dragging them around but if you sit with your legs raised you will soon be sitting in a puddle.

At the follow-up appointment, I told Dr. Wilson "Please don't tell me that you didn't find any cancer." But that's exactly what she told me. She did say they found cancer in my prostate. I was surprised.

I read all of Dr. Wilson's handouts and I have a few comments: The description of Kegel
exercises is covered in two of the handouts. They list quite different methods, but I get the idea. I have been doing the exercises religiously since my surgery in February. One of the handouts has a chart listing frequency of urination. This chart is unrealistic. During the day, I can't go longer than 4 hours. I can tell when I need to go and I am wearing normal underwear during the day. At night, I need the Depends. I try to wake up every two hours. Even at that frequency, I still have leakage. The handout states that I could have incontinence for up to a year. I'm not making any progress at night and it doesn't look good for the future.

Here's another tip: There are two ways I can tell when I have to go (during the day). First of all, I am still getting a bit of mucous forming at the bladder exit. I can feel when this starts to move. Also, if I wait too long, I start to feel pain in my kidneys.

Since you ask, I do have a couple of questions:

Sleeping means relaxing. Relaxing means leaking. Isn't there anything I can do?
Will I ever have an erection again?

In summary, I am still a little doubtful that I needed this surgery. University Hospital is an excellent facility. Dr. Wilson is an excellent surgeon and her nurses are top notch.

Patient would like to remain anonymous. Please respect their privacy.
Research neobladders as much as you can. There is a vast amount of information on medical websites to help you with this. Once you have your appointment with Dr. Wilson, you will also be informed how they do the surgery. One of her doctors on staff even drew us a picture to show exactly how they hook your new bladder up.

We appreciated the fact that Dr. Wilson's team kept my wife informed while waiting during surgery, which helps to lower her anxiety during the surgery. My surgery lasted 7 and 1/2 hours, so prepare your family that it may be a long day for them.

After surgery, walk as much a possible... in the hospital, as well as after you go home. Be prepared that your appetite may be very poor for awhile. Nothing tasted good no matter what it was. I lost 10% of my body weight in the 4-6 weeks after surgery. I have since gained back 5%, which puts me at a very good weight. Also, be prepared that you will be very weak, and that you will be needing a couple of naps during the day. I don't nap anymore on a regular basis, but if I feel tired I go take a nap.

After the catheters came out (3 weeks after surgery), I had a lot of incontinence and was getting up every 45 minutes during the night to void. I am 4 months post-op now and it has improved greatly. However, in order to get a good night's sleep, I started wearing an external catheter during the night only. It was a relief to get a good night's sleep! There are companies that will let you try several different catheters for free, and after that, Medicare helps with the expense, keeping it reasonable (less than $10 a month). You have to use a new one every night. There are a lot of pads, etc. to help with incontinence, but I have found that a triangle shaped one called Guards and made by Depends is the most effective for me.

I found that you can't wear boxers anymore, due to holding the pad in place, but briefs work well. In preparation for home care, I recommend you buy some large pads for your bed. My wife got ones that cover approximately 3x4 feet and they will save your bed and linens in case of a leak or spill.

Dr. Wilson and all of her medical staff were outstanding and communication was excellent.

My recent PET scan showed no recurrence or metastatic disease seen throughout.

Thank you so much. If anyone of your patients has questions or wants to talk to someone who has been through this surgery, you may reach me at 6155smith@comcast.net.

Best Regards,

Terry Smith  
Colorado Springs
My name is Nancy Brown. I had my bladder removed in November of 2011. I was in the hospital for two weeks. I read books on my kindle whenever I was awake.

For the first three months after I got out of the hospital we stayed with a daughter until I got my strength back and had sufficiently recovered. Unfortunately, I remember nights of a leaking bag. Part of the trouble is it takes some time to figure out the right medical equipment.

One of my frustrations was that I didn't know anyone else with this situation and we lived too far away from a support group to get any help from that source. We changed the bag three times a week and I needed to empty about every hour.

Over the period of five years I developed a peristomal hernia. This makes it a lot harder to change the bag because the surface is no longer flat. In September of 2016, I had two surgeries to repair this one week apart. It was successful. Now I change two times a week and can go longer without emptying. I use the two-piece system, which has worked quite well.

I am grateful for my two surgeons, Dr. Shandra Wilson and Dr. Susan Hagan, of Boulder Community Hospital. They were both personable and excellent surgeons.
I would like to share my experience on my decision to have the bladder replacement surgery. I have always had a small bladder and have had to urinate more frequently. At the age of 52 I also started experiencing a burning sensation. My family doctor sent me to see the local urologist. I spent three years following the normal protocol of trying every medicine available. I ended up being diagnosed with severe Interstitial Cystitis. I kept developing ulcers in my bladder which lead me to keep having hydrodistention done every three-to-four months. I tried Botox with no prevail. The urgency and burning just kept getting worse that I couldn’t even go out to dinner or make it through a wedding without many trips to the bathroom. I wanted to try all options before considering a bladder replacement. At this point I decided to try the Medtronic Bladder Control Therapy. I had surgery to implant the device in my rear cheek. I thought it helped during the trial period but soon I was back to square one. Ten months later I was in so much misery I opted to have the Neobladder Replacement Surgery which was basically my last option. I chose the option to have the neobladder attached back to the urethra so there would be no need for any external bags.

I spent nine days in the hospital following the surgery. I can’t say that this part wasn’t hard. For a week straight, I did nothing but throw up. I did have a small leak in my new bladder that my have contributed me being sick for so long. On the seventh day, a lot came up and after that it was like night and day. Three weeks later all the catheters and tubes were removed and the leak had healed on its own in my new bladder. At first it was a real eye opener not to have any control of my urination. I had to set my alarm every two hours to urinate. I am now two and a half past my surgery and I feel 100% better. I can now go out to eat and not even have to go to the bathroom. No more burning and no more pills! I now get up somewhere between three-to-four hours to urinate at night. I wish I would have done this surgery a long time ago. It’s the best I’ve felt in years and feel like I can live a normal life again. I highly recommend this surgery and was very satisfied with Dr. Wilson and her staff.

Thank you and hope this helps.

Tommy R. Collins
Dear Patients,

I am sure that many other patients will have the same difficulty I have in trying to distill down some helpful comments, especially after experiencing the incredibly supportive, inspiring and obvious technically expert care I have received from Dr. Wilson. Her care is a model of what very personal, patient-centered care should look like.

I’d like to check before I send anything redundant whether anyone else has suggested https://www.inspire.com/conditions/bladder-cancer/

As a source of support from past and current patients as well as occasional releases of information from the experts.

Warmly,

Frank Dornfest
Hello Patients,

We appreciate your trust in us, as patients/spouses to share information with others who are faced with extensive bladder cancer and are facing radical cystectomy and/or other types of treatment.

The road is long and incredibly stressful though our best advice for others is to trust in the expertise of Dr. Wilson and the other Urological Oncologists at Anschutz Medical Center. Dr. Wilson and staff were honest, never misled us, presented us with options and always offered us hope and encouragement through every part of the journey. They also took the time to address all of our concerns.

It is incredibly difficult to re-visit that time of our life and it brings forth painful emotions that, for the most part, we’ve now managed to bury. That was such an emotionally painful time in our life, that that we almost didn’t respond to share our experience. However, we also remember that it was talking to others that had been through the surgery/testing/recovery process that helped us to keep our sanity and our faith.

Our reactions to the diagnosis, plan of treatment and entire journey were vastly different from each other though they held the common themes of fear, grief and being faced with the thought of mortality for the first time in our lives. My husband had no medical background though clearly knew his mortality was at stake and states “It changed my life. It was a hard time in my life and I was not sure what was going to happen to me. It was very scary but it helped that I was able to talk with someone I knew who had went through it”. I, having been a registered nurse since 1986 with a post-baccalaureate education, was both blessed and cursed. I had a solid understanding of what was going on but also knew too much about the risks associated with the diagnosis and surgical procedure.

My husband Brian was only 44-years-old when his extensive bladder cancer was diagnosed, so to say that the diagnosis caught both of us off-guard is an understatement. He was 100% healthy (or so we thought) with no acute or chronic medical issues. His cancer was literally found “by accident” and we were stunned. Brian was pretty silent throughout the process other than saying “I am not going to let this cancer win”. I, on the other hand, cried… a lot and sometimes I screamed but only when no one was around to hear me.

I specifically remember a cruise vacation that we had planned prior to knowing of his cancer. The cruise was to occur after his diagnosis and shortly before his scheduled surgery. We, of course, were going to cancel it until we were told by his urologist that this might be our last chance to go on vacation with each other since Brian’s future was so uncertain. For me, the vacation was tainted with the “what if”s”:

“What if this is our last vacation together?”
“What if this is the last time we get to enjoy a glass of wine overlooking the ocean?”
So, while we enjoyed the journey, I’m certain we were both aware that it could be our last.

Then came the surgery… almost nine hours from cut-to-close for which he got to “sleep” and for which I got to spend time with family members who were in such denial that they honestly didn’t understand our grief and fear of the unknown. Post-operatively he suffered pain but was cared for by AMAZING nursing staff at University Hospital that were compassionate, caring and skilled. Some of those individuals have now become lifelong friends who continue to celebrate each year of Brian remaining cancer free.

I never left his bedside during the time he was in the hospital and perhaps the best advice that I can give to other spouses is to stick with your gut instincts because no one knows your spouse better than you. So, if you feel something is “wrong” than follow through like a squeaky wheel until you get someone to listen to you, provide follow-up and resolve whatever issue is present. For example, one night my husband was in excruciating pain that was completely unrelieved with pain medications. I knew he had a very high pain tolerance but the medical resident that I summoned to his bedside in the middle of the night did not. The resident tried to tell me that he (my husband) was just “being a little wimpy” and that he would order different pain meds. I insisted this was not the case and firmly stood my ground until the resident performed a more complete assessment to ultimately discover that one of my husband’s nephrostomy tubes (a tube to drain the kidney) was clotted off and the pain was from his kidney not being able to drain.

Going home and learning to live post-operatively was an entirely different adventure. For the patient, it is learning to live with an orthotopic neobladder (or ostomy) and learning how to become “normal” again. Our advice is to use the helpful resources that are offered to you. Attend the educational groups and call on others who have been through this before you. The first year is perhaps the most difficult. On top of wondering what the next PET or CT scan will show, you are adjusting your lifestyle to accommodate your medical needs. Perhaps you will have to learn to complete urinary self-catheterization, be subject to urinary incontinence issues or require assistance with resuming a normal sex life. Be aware that everyone’s experience is different but also be aware that you are not alone. If you are a patient, talk to other patients who have went through this. If you are a spouse, talk with other spouses as the one thing we found out is that our experience (patient vs spouse) was completely different from each other and as much as we may have tried, we didn’t always understand what the other person was going through.

I know this is a very frightening process. My husband almost died when he threw multiple blood clots shortly after our return to home. The fact that he lived was nothing short of a miracle and we have cherished every day since that time. With each passing day of recovery our future seemed brighter… though we were also fearful of the return of cancer. Follow-up visits were met with excitement that we might hear good news again and fear that the news might not be so good. Planning for each follow-up visit was an emotional roller coaster of sorts that became smoother with the passing of time.

As it turned out, our future had a happy ending. After having been cancer free for five years after the surgery, Dr. Wilson called Brian “cured” and this past August of 2016, he had been cancer free for six years. We truly credit Dr. Wilson for saving his life and have no doubt that he would not be here without her skill and expertise.
Our lives are “normal” now… or we call it our “new normal.” Brian has learned to live with his orthotopic neobladder so well that I almost forget that he has one at times. We’ve had to give up some past hobbies such as scuba diving (because of barometric pressure changes that his neobladder would not withstand) and skiing (due to lifelong Coumadin use after suffering the blood clots) but we’ve replaced them with other activities and now have built our dream home where we will hopefully celebrate many anniversaries and grow old together. This past summer, Brian celebrated his 50th Birthday… a milestone that most people take for granted but one that we celebrated with vigor as it was never promised.

We’re hoping that Brian’s success and eventual recovery to be able to hear the words “cancer free” will encourage others as they travel along a road filled with uncertainty. Brian ends our submission by saying “I am glad that I am alive and able to live a full life and maybe be able to somehow help others that are going through the same thing.”

Respectfully and sincerely submitted,

Brian & Kathy Trogden
Email: canonkat@bresnan.net

P.S. As Brian and I were talking about this, he did mention that the only thing he would do differently (associated with sexual difficulty) would be to NOT have his prostate removed and be allowed to explore other treatment options for the prostate cancer (it was not a metastasis from the bladder but a different cancer). As it was, Dr. Wilson made the decision during surgery to remove the prostate and Brian was not able to participate in that decision.
My Fellow Patients,

I woke up one Sunday morning to pee blood, and I said to myself, “THIS DOESN’T SEEM NORMAL,” and my journey began.

My name is John Mueller and I will tell you my story. While there is absolutely nothing humorous about the “C” word—I choose to inject some humor into my tale. I firmly believe that if a person can smile things just seem to go a little better.

After being diagnosed with stage four bladder cancer it felt like someone let the wind out of my sail (or about 30 seconds). Then I got serious. I got hooked up with a urology company that almost sold me a bill of goods- and a canvas anchor for my side. That relationship was indeed a fleeting one— and then I found LOVE!!! (UNIVERSITY OF COLORADO AND SHANDRA WILSON!!) I don’t know what happened but I think the University found a different partner, and I know Shandra did! That’s my luck! But, I did get a new bladder to replace a broken heart. Not bad!

Seriously now, here is the things I would like to share with you:

1. Get yourself in reasonable shape before your surgery—It helps the healing process.
2. Be pro-active—learn all you can to help you make good decisions about the direction you choose!
3. Get up and get moving as quickly as you can after your surgery—It will do wonders for the healing process!
4. Develop and maintain a positive attitude—you can’t change the fact that you have cancer, but you surely can change the outcome!
5. Some days will be tough, emotionally and physically, but push through—tomorrow is a whole new day!
6. Find joy in everything! Stay positive! Live like you’ve never lived before!
7. The team! What can I say? The nurses, the hospital, the care I received, were all PHENOMINAL!

I could never imagine going anywhere else for this care! Dr. Wilson and her team are the best I could ever dream of and I couldn’t be more pleased with the outcome. It’s like a whole new opportunity to live and enjoy my life. There is a little quirk here and there, but I expected much worse. Well, I better close for now (I have to plan my tomorrow!!)

Godspeed and get well,

John Mueller
My name is Sharon Golden and had neobladder surgery from Shandra Wilson, I believe in 2010. The hardest part was deciding what kind of bladder to have and feeling very much alone because there was so little information on bladder cancer. I never smoked or worked with chemicals. I was shocked to find out I have bladder cancer. My twins were only eight-months-old when I found out and I had chemotherapy. Dr. Wilson gave me the names of two people to talk to in helping me decide what type of bladder to go with, but it really didn't tell me a lot.

Also after my surgery I was not aware that you could do Kegel exercises to possibly strengthen your new bladder muscles. I was in pain and found out it was because I was not completely voiding. I was told to self-cath part of the time to help. I saw a physical therapist who taught me Kegel exercises, but it was too late by then. I always have to self-cath now. I am unable to void on my own and have no feeling until it is urgent. I recommend to anyone who has a neobladder to find out about Kegel exercises and start right away. I am fortunate that I have never had incontinence, except for the first few weeks. The Kegel exercises can help with this. A frequent problem I had and hear about with neobladders is frequent urinary tract infections. If you are using a catheter, use a clean one each time and make sure you are drinking more water and voiding often. This can help but some people still have problems. I have decreased and am more sensitive, but being more cautious has reduced the infections. Also, after my neobladder I had stomach pains, loss of bowel control and vomiting. I was thankful to be given the prescription of cholestyramine for that. I just take it every other day. It's a powder mixed with juice. It's amazing! If I know I'm eating something heavier it's okay to take a second dose. My body is more sensitive and can feel discomfort, but I am active, healthy and grateful to be alive and enjoy my children and husband.

The best advice I can give is seek out the bladder cancer network. Take time to search on different types of bladder options and ask people questions. Do not be afraid to talk to your doctor with questions. Your body will be changed and it's okay to talk about and learn what is "normal" and something to look out for. The BCAN site was amazing for me to discover later on and not feel alone. You can journal on there too. Hang in there and remember to look for support and know you can't do it all.
First and foremost, I am where I am today because of her talent, compassion, and competence. I also need to include my Primary Care Physician at our clinic, my Urologist, Oncologist, Dr. Wilson’s Urology team and the nursing staff at University of Colorado Hospital. Having said all that, the following is my page . . .

During my chemo and prior to surgery, I devoted at least 1 hour, 6 days per week to exercise at our local YMCA. I ate a sensible diet (most of the time). Most mornings I would also drink (a rather terrible tasting) smoothie with pomegranate juice, spinach, beets, chlorella powder, turmeric, and blue green algae - a concoction my daughter came up with. There are probably folks who come through this surgery just fine without such preparation, but I truly believe it helped me – especially with my recovery once out of the hospital.

As for my recovery, I was back in the YMCA three days after getting my catheter out – just walking at first, but within a few weeks, I was actually starting to look and feel like ‘myself’ again. I think it’s important to mention this because it wasn’t easy. Staying on the couch seemed much more pleasant. I also joined a group of guys who meet once a month to share our experiences. This group is actually guys who have been through prostate cancer, but, in a small town, this is “close enough.”

Now, the pitfalls . . . Directly following surgery, I felt “pretty good” and had a rather cavalier attitude, so I thought I could just start eating real food right away. BIG mistake. Not taking into consideration I had a section of small intestine repurposed and re-attached, it was nowhere near ready for food. This, I believe set me back considerably and I was hospitalized several more days than I anticipated. My advice here is to give it a day or two, then start SLOW. Like jello, broth, etc.

10 months after surgery, I feel great and have no limitations, even my sex life is good. Daytime continence and bladder emptying is no issue and I can pee faster than my friends :). Nighttime incontinence is annoying. I have it mostly under control but still wear “protection” for those nights where things aren’t perfect. I sort of kept a log and find that [for me] diet or drink have no effect, either positive or negative. Contentment, no stress, and being conscious of it have the positive affect, and this situation is still improving. In the big scheme of things . . . this annoyance is pretty insignificant.

Gregg Pevoteaux
My Journey through Bladder Cancer and Surgery

I had a very intensive surgery so thought maybe I could help be a support for someone else.

My journey started in June 2014 when I lost my wife of 45 years. Then, in November, I was diagnosed with bladder cancer. I went in for surgery to my local doctor in Durango, CO but after starting the surgery, my doctor determined that there was a need for more intensive surgery by a more experience team. All of my children and some grandchildren were there for that initial surgery. After much discussion and prayer, we made the decision to go ahead as our doctor suggested and go to Denver and have Dr. Shandra Wilson and her team do the surgery.

That 2nd surgery was done on Dec 31, 2014 to remove the cancerous tumors in my bladder. Dr. Wilson performed the surgery, and again, every one of my children (6) and some grandchildren were there. I believe it helps to have family support. I came home and traveled to Durango hospital once a week for ongoing treatment for 9 weeks. At the end of that period, they ran more tests and found that the cancer had returned. The doctors said that the best chance of survival, I had was to have my bladder removed.

When the decision was made to remove the bladder, I was given a couple of options: 1) Remove bladder and wear an external ostomy bag or 2) Remove bladder and rebuild an internal bladder called an Indiana Pouch and learn to catheterize myself through it.

It was a very hard decision to make and especially at the age of 82, but my family and I discussed it and prayed, and ultimately, they said it was my decision to make. My family was and still are very supportive. I chose the Indiana Pouch option.

Surgery was performed on Aug 5, 2015 by Dr. Shandra Wilson and Dr. Paul Maroni and lasted nearly 8 hours. I had several complications and had to spend 30 days in the hospital. Initially, the doctors had hoped for only 7-10 days. Again, my children were all there and stayed for 2-3 days after surgery. Most had to return home to work. My daughter was there with me every minute, and never left me for the entire time. There were a lot of tears, prayers and at times, I was ready to give up. My daughter kept me going, reminding me to never give up, that I had so much to live for and so many family members and friends that loved me. It has been 18 months now and I am still doing pretty good. I have my days, but I can’t give up!

I had the best care possible at Colorado University Hospital, Anschutz Pavilion with Dr. Shandra Wilson and Dr. Paul Maroni. The doctors, the nurses, and the entire staff were awesome. The way that they care for you completely, with different specialty teams for each issue, was just amazing. Prayer and family support were the two most important things to keep me going, but I can’t discount the care from any of the team at this hospital.

My thoughts and prayers are with any of you that are experiencing surgery. I pray it will work out for each of you and God bless Dr. Wilson, Dr. Maroni and their team.

Thank you,

Harold L. Foster, Sr
My name is Richard Stanley, I am a 77-year-old man, who had suffered with repeated incidents of Carcinoma in Situ for over 35 years prior to having bladder surgery. I was treated with BCG & Interferon until late 2007. At this time, I needed to have my bladder removed and a decision needed to be made wither to replace my bladder with a neo-bladder or to have a stoma placed in my stomach.

My wife and I discussed this procedure and talked over the advantages and disadvantages of each type of surgery. We also talked to several other patients about to get their input. Due to the invasion of the cancer, my prostate was also removed during surgery. I have become both impotent & incontinent as a result of this surgery. I have to catheterize myself twice a day to make sure that I do not retain too much urine. It helps to practice core muscle strengthening for good urine retention.

I contracted an infection, which made recovery slow, and required me to remain in the hospital and a rehab center for 2 ½ months.

The loss of sexual performance has created tensions in my relationship, and this should be explored diligently.

Suggestions:

- Talk with your spouse & others about your intentions and ask about side effects and expected results.
- Talk to your doctor about procedures and recovery and potential outcomes.
- Check any allergies you have and share all with your surgeon.
- Be realistic about your expectations.

I am happy to be alive, but there were more side effects than I had expected. **THIS IS A SERIOUS SURGERY!**

**Final note:** the staff at UCH is been excellent and very supportive. Not only during the procedure, but also throughout the follow-up process.

If you can, when this project is over, I would like to know how it turned out. I would also be available to talk to anyone about my experience.

Thank you,

Richard Stanley
My name is Orville English. I had bladder removal, prostate removal, neobladder surgery on September 17, 2015. First of all, I want to send my undying gratitude to Shandra and the entire University of Colorado medical staff for keeping me alive and providing me, my family and friends many more years of sharing our love and spending time together. I believe I am doing very well now. I'm 65 years old, still working full time and doing many activities that I've always enjoyed, including walking, golfing 18 holes, hiking in the mountains and skiing. All of my follow up CT scans have been clear and show no signs of recurring cancer. I thank God, every night for your intervention. Unfortunately, I still have some peripheral neuropathy in my feet, haven't regained full control of my neobladder during sleep, and have erectile dysfunction. Here are my observations and suggestions.

1. Chemotherapy phase and preoperative period: Keep very active, regular workout routines, walking, golfing, etc. Basically, do whatever you can do to keep up your strength. Keep eating and hydrating, you'll need it all later. My memory and all of my senses got out of whack during this time. Get instruction on how to do kegel exercises and do them. You will need strong kegel muscles after surgery to help gain control of your new bladder.

2. Post-operative period and hospital stay: Try to get out of bed and walk as much as you can as soon as you can. Take advantage of the physical and occupational therapists input. Use the calf pads as directed. My calves got really sore, so I backed off using them as directed and I developed a blood clot as soon as I got home. That clot led to and emergency readmit, another night in the hospital, and 3 months of two a day shots to dissolve the clot.

Additionally, I had a great deal of trouble sleeping in the hospital. Hospital staff are doing their scheduled procedures 24/7, I frequently had cold sweats at night and I couldn't get enough covers to stay warm. I was given Ambien for sleep. I don't think it helped me to sleep, but gave me hallucinations all night long. I became very sensitive to cold, even though the room temp was about 72. Make sure you have warm robes, slippers, etc.

Many medical staff teams came in throughout the day, asked many questions and told me lots of information to remember. Try to always have family members or friends present during these visits so they can help you remember what has been happening to you, questions you might have thought of, and to help you remember what the staff tells you. Try to keep busy during waking hours. Activities like TV, music, reading or hobbies will help the time go by. Personally, I had very little interest in anything. I had no appetite and could hardly eat anything for days. I also couldn't/didn't drink enough fluids to keep hydrated. You are on an IV all the time but should still hydrate as much as possible.

3. Post-operative period and going home: Sign up to have nurse visits, physical and occupational therapy to come to your home. They will work you out, challenge you, answer your questions, motivate you and give you a number of things you can do independently to recover. DO THEM RELIGIOUSLY, even if you don't feel great, even if you're tired, even if you're having other complications. I would spend between 1-2
hours each day doing walks, stairs and other exercises. I think it was a huge reason why I got my strength back as quickly as I did. Before chemo and surgery, I would walk 10-15 miles hiking the mountains or walk 18 holes of golf and think nothing of it. After surgery, just walking around my living room a couple of times was draining and tiring. That's how much energy and vitality you may lose in such a short period of time. Because of this, you must keep working, challenging, and pushing yourself to do more every day, if you're able to. But don't be too hard on yourself. Give yourself permission to slack off every once in a while. I had problems with diarrhea for quite some time after I got home. Get meds to help you out if needed. My bottom hurt/was sore for weeks. I sat on pillows. But, even then, I kept pushing and tried not to use it for an excuse to slack off. Keep doing the kegel exercises after they pull the tubes out and remove the catheter. This will help you to be able to control the new bladder. My PT had me do 10 sets of 10 repetitions several times a day, if I could handle it. To this day my memory is still not what it was. I'm 65 years old, so maybe it's also just a normal part of the aging process. For the most part, my blood tests indicate that, a year and a half after surgery, I'm back to my baseline.

Make sure that you stay on track with your CT scans and doctor check-ups. It's important to know if you're cancer free. You also may have ongoing issues to discuss with your oncologist. For me, it was important to have my port removed as soon as I was given the approval from my doctors. Having the port removed helped me feel like I was back to my old self and leaving the cancer issues behind. Make sure you get insurance approval for CT scans and other post-surgical follow-ups. You don't want to get stuck with a bill that wasn't approved.

I hope this has been helpful to you.

Sincerely,

Orville English
No matter how you cut it, your recovery time, assuming no complications, will be 6-8 weeks. That is technically recovery time, in reality it will be several months after that before you have your full energy back.

The best thing you can do in terms of recover is to walk. Walk. Walk. Walk. Then walk some more. Walking will help to get your bowels moving, help prevent blood clots and help your breathing after surgery. Once you’re home, that is where most of us tend to relax. Make it a priority to continue to walk.

This is a very major surgery and although it isn’t as bad as we imagine it will be, it still takes the body time to heal. Being in good shape will help you, but be sure to give your body the time it needs to heal. If you try to push yourself too quickly, it will only set you back. So, plan on taking it easy for as long as it takes for your body to heal.

**Tips for the Hospital –**

1. Don’t try to be a hero! Use the pain meds they provide for you.
2. When they let you eat, only eat small amounts of easily digested food.
3. Use the stool softeners as long as you’re taking pain medications.
4. Drink lots of water.
5. Taking chewing gum with you. If they let you have it, it will help wake up your bowels.
6. Use the incentive spirometer!!! Get one before surgery and practice with it. It makes it easier to use post-op.
7. While in the hospital, those lovely gowns are actually the best things to wear with all the tubes, IVs and possibility of leaks. Put one on forward and one on backwards, so that all body parts are covered and you are set to roll. If the halls are chilly, you might like a nice comfy bathrobe from home.
8. Be sure to take slip on shoes or slippers with you to the hospital so you don’t have to bend over to put them on.
9. Here are some other items you might like to bring from home:
   a. Refresh eye drops with optive and saline nasal spray—the hospital air is very dry.
   b. Hard candies and/or ricola cough drops.
   c. You might prefer your own toothbrush; the hospital ones are small and hard.
   d. Electronics to pass the time: iPhone, iPad, Kindle, etc.
   e. 6’ extension cord charger to recharge from bed.
   f. ear buds.
   g. compression stockings, your lower half will be swollen.
   h. Eye mask and ear plugs.
   i. Sweatpants, a shirt that buttons and a warm jacket that zips to go home in.
   j. Pillow in the car to put between your stomach and seat belt on the ride home.
   k. Keep an empty jar or water bottle in the car just in case you get stuck in traffic and need to empty your pouch.

Following is a list is ostomy product manufacturers. Call each one and request samples of their urostomy pouches, both two-piece and one-piece, flat and convex. They will be happy to send samples to you. There are links for night bags, extra lengths of tubing (to give you a total of 10 ft.), a leg band to prevent twisting at night and disposal bags.
The disposal bags are cheap and I like them because you can't see through them like you could a Ziploc bag. They are also handy for carrying an extra pouch in your purse. If you ever have to use it, you will have a disposal bag as well! A word of caution... hold off using convex pouches for 3 - 4 weeks until you're healed.

Your stoma will decrease in size over the 4-6 weeks after surgery and then reach its final size. You want a stoma to be at least 2 inches long and protruding from your abdomen so that it will stick out into the pouch. Stomas that are flush with your skin or are "innies" have a bigger problem with leaking. Ask your surgeon, if at all possible, to give you enough length on the outside. Longer stomas are not as "cute" as the ones flush with your skin but there is nothing "cute" about having to deal with leaks.

Manufacturers -
Coloplast – 1-800-533-0464
Covatec – 1-800-422-8811
Cymed – 1-800-582-0707
Hollister Wound Care – 1-888-740-8999
Marlen – 1-216-292-7060
Nu-Hope – 1-800-899-5017

Here are some pouch changing suggestions:
10. If you use vinegar/water solution to wash, it might sting at first.
11. If you change pouches first thing in the morning, about a half an hour after getting up and before having anything to drink, there will be very few “dribbles”.
12. There is no need to use adhesive remover when changing your pouch, unless you use extra sticky hydrocolloid ringer or moldable wafers. A little adhesive remaining from the old pouch will only help the new one to stick better. However, if there is a lot of leftover adhesive, it needs to be removed.
13. Products like Uni-Solve adhesive remover work well to remove excess adhesive.
14. When it comes to pouches, less is more. Pouches stick best on clean, dry skin, so avoid using powders, skin barriers, pastes, etc. unless absolutely necessary.
15. Be aware that many ostomy nurses do not know a lot about dealing with UROSTOMIES and the corrosive effect that urine has on products made for other types of ostomies.
16. Home healthcare nurses know even less than hospital nurses do, including even those who say they are ostomy nurses. If you get a good one, you are among the very lucky.
17. Mucus is normal. Your stoma is made from a piece of intestine, which naturally produces mucus. The more water you drink; the less mucus you will have.

To change your urostomy, I recommend the following steps:
1. Remove the old pouch or wafer by loosening the edges a bit, then pressing the skin away from the pouch. Be careful not to pull the pouch away from the skin.
2. Wash the skin and stoma with plain water, 50/50 vinegar/water solution or, if showering, wash with baby shampoo or ivory soap. Baby shampoo and Ivory soap have little or no moisturizers that will compromise the adhesive on the pouch.
3. Vinegar will neutralize any urine on your skin.
4. Dry the skin with a towel.
5. While holding a piece of gauze over the end of your stoma to catch drips and leaning forward slightly, dry your skin with a hair dryer until it is thoroughly dry. By leaning forward, any drips will fall to the floor, not on your skin. You do not want any urine on you skin under the adhesive.
6. Apply the new pouch, making sure that the bottom of the opening is against the bottom of your skin.
7. Stick it on from the bottom to top.
8. Heat the wafer/pouch with the hair drier. Then, hold your hand over the adhesive part of the pouch for a few minutes to get a good seal.
9. **Again, the keywords – less is more.**
10. Go ahead and have a glass of wine :)

**To clean the night bag and tubing:**

1. Empty the urine and close the drain.
2. Mix about 1 cup of cheap (dollar store) mouthwash with some hot water in a condiment bottle (buy at the grocery store or kitchen supply store).
3. Squirt it down the tube into the bag.
4. Swish around, then drain out the solution and reclose the drain.
5. Hang the bag up until the next use.
6. The night bags will last a long time.
7. As long as the bag is lower than your body, there is no risk of infection or reflux from the bag.
8. Whenever you travel, take two, “just in case” …
9. Waterproof mattress cover—buy at Bed, Bath & Beyond or any other linen store. Get the thin kind and use your regular mattress pad over it.
10. Buy a couple of crib sized, flat, waterproof mattress cover pads. They can be used under you in bed to avoid soaking all the bedding if you have a leak. Use them if you are napping in a chair or on the couch, “just in case”. They are much more comfortable than the blue pads used at the hospital.
11. Comfy sweatpants or yoga pants with wide, stretchy waistbands.
12. Slip on shoes or slippers—you need these for the hospital too.
13. You will need to change to “tighty whities” if youre wearing boxers. Gotta keep the bag held tight to your body. Of course, that’s assuming that you end up with an ileal conduit.
14. Ostomysecrets.com offers special ostomy underwear with built-in-pouches to hold your urostomy pouch. Some people like them, others don’t. They tend to be quite expensive.
15. Order extra lengths of tubing for your night drainage bag.
16. Order a couple of leg bands to hold the night bag tubing in place.
17. Buy some cranberry juice to have on hand and vitamin C tablets. They will each help keep your urine acidic, which is easier on your skin and will help keep the odor down.
18. Buy protein drink, such as ensure or boost. If you can’t tolerate these, then get protein powder to mix with milk or soy milk. Protein is essential for healing, so even if you have no appetite or if food tastes bad, still drink some protein. Add ice cream if it helps. Don’t by a lot of the ensure until you’re sure that you can tolerate them. Remember that your
intestines are going to be healing and what was good before might not be good for a while after.

20. Buy some white vinegar and baby shampoo or bars of ivory soap to wash the skin around your stoma.
21. CovaTec makes a perennial skin cleaner that is low-pH and doesn’t need rinsing.
22. Your home care nurse will help you with ordering supplies and the hospital will send you home with some.
23. Don’t count on the home care nurse knowing much about urostomies!
24. 4x4 gauze pads are good for washing around your stoma and for holding against the end of it to catch drips. You can buy large packages cheaply at medical supply stores. Don’t pay drug store prices!
25. Buy a small mirror on a little stand so that you can use it to see your stoma as you are changing pouches.
26. Plan on eating frequent, small, easily digestible meals for several weeks. Avoid things that are high in fiber, such as raw fruit and most vegetables, unless cooked very well.
27. Outside of that, after swelling has gone down, you will wear the same clothes that you wore prior to your surgery.

Please feel free to e-mail me if you have questions.
idpaschal@hotmail.com

Thanks,

Jonathan Paschal
Dear Patients,

I was diagnosed with small cell bladder cancer almost 4 years ago. Researching online, I found that the average lifespan with this type of bladder cancer was approximately 2 years. When I found out how deadly small cell bladder cancer can be, I was devastated. After much prayer and introspection I proceeded forward.

I had been seeing another doctor prior to Dr. Shandra Wilson. However, as I felt he was not the best match for me, my wife found the Bladder Cancer Advocacy Network and their INSPIRE blog. Through this, we found stories of patients with similar diagnoses to mine, that had been through surgery and recovery. We gained insight and wanted to choose a surgeon who did the most cystectomies in the state where we live. Through the Bladder Cancer Advocacy site, we used www.inspire.com and searched for Colorado. I came across Dr. Shandra Wilson’s name as the surgeon who performed the most cystectomies in the state of Colorado.

We looked her up and found that she had a thorough website, explaining many of different aspects of bladder cancer and the whole stages of surgery and recovery. After reading that she truly cared about her patients and would even answer emails, we decided to email her. In less than 2 hours she responded saying she would love to see us. WOW!! We were able to see her the next week and have surgery 2 weeks later. What a caring and informative doctor!

The first surgical option presented to me at another facility was the Indiana pouch (an ileal conduit). However, Dr. Wilson said that because I was in good condition and the fact that it appeared as though my ureters were not affected, that a neobladder would be excellent for me, which functions the most like a regular bladder.

I was told I should probably not expect to return to work until 8 weeks (as this surgery is harder on the body than heart surgery) and then it would be part-time working up to full-time. I returned at 4 ½ weeks and by 5 weeks was back to full-time. Of course, I worked very hard to get my strength back. At first, several times a day, I would walk the hall and kitchen. After getting stronger, I would get on the treadmill and put it at the slowest speed. From there, I progressed to using walker to go down to the bottom of the driveway and back up. I worked on going to the mailbox at the far end of our property; from there to the end of the block and back. Then around the block, then two blocks, all the while gaining strength. Eventually, I progressed to walking without the walker, with my wife close by, moving ever so slowly. After three weeks, I used extremely light weights (1 to 3 pounds) to build strength while I was seated.

I was very lucky. With the help of my oncologist, I chose to NOT have chemotherapy or radiation because, according to the pathologist report, the cancer seemed to only be confined to my bladder and not invasive. I had my bladder out first due to some important events that I had to attend. I know some doctors want you to have chemo or radiation first. However, I made the decision that I felt this was best for me. I am so glad I did.
As far as suggestions:

1. Make sure you have doctors you trust. From the first sign of blood, to the removal of the bladder and follow-up, I was blessed with amazing doctors and surgeons.
2. Don’t delay treatment, even one week. There are certain types of bladder cancer that are very invasive and spreading. Once that happens, treatment becomes much more complicated.
3. Set up an appointment in the sixth week after surgery with a bladder muscle therapy nurse at Rose Medical Center. Insurance does not usually cover this, but without her, I would not have any control. To this day I still use light liners. My leakage is just a few drops occasionally, especially with lifting, or physical exertion.
4. Have certain items at home that are ready for you after surgery.
5. Ice chips.
6. A wedge pillow that we ordered from Amazon. This helps with all the lying down you will do (and watching TV) and eases the pain from the stitches, internal and external.
7. A raised toilet seat, preferably with arms.
8. A shower seat or bench. Not for you to necessarily sit on, but to place all your bags from the stents and catheter. I had three bags for a week.
9. Pull up adult diapers and large absorbent pads. If you can get three hospital gowns that would also be great. You will go through a lot of these after the first week when they pull out the stents and catheter, as you will not have any urinary control for quite a while.
10. Blue waterproof pads in addition to a quilted waterproof sheet protector for the bed. You will use the waterproof pads everywhere you sit on couches and chairs.
11. Have plenty of Ensure type drinks and smoothies ready. I lost 20 pounds, even though I kept drinking those. It is like your intestines don’t absorb what they need to, due to the removal of the 18 inches to make the neobladder.
12. Soft foods to aid in digestion.
13. Nightlight if you don’t currently use one. You will need to relieve yourself starting every 2 hours through the night and day. Eventually you will get to every 4 hours.
14. An alarm on your nightstand or your cellphone. Again it will need to be set for every 2 hours initially, gradually building up through the weeks to every four hours. You will have no feeling of when you need to go to the bathroom, so setting an alarm will help any accidents happening at night or during the day. If you happen to drink extra due to the heat or an evening out having a couple of beers, move the time up. You do not want the neobladder to stretch out very much or it will lose what little elasticity it has and leakage will be a big problem the rest of your life. Think of a balloon that has been blown up to its max and then the air released. It would be quite saggy.
15. Keep an extra set or two of clothes at work. Accidents and or leakage are going to happen. I kept mine at work for the first 7 months.
16. Opt for the nerve sparing surgery. It does increase the amount of time you are in surgery. It was supposed to increase the chances of an erection, but in my case it didn't. However, I believe that it did help in that after a year, I had a feeling of pressure when I have to go to the bathroom.
17. Surround yourself with a good support network. Our church prayed for me that the cancer would be confined to the bladder and it was. They prayed for a speedy recovery; and compared to others, it was.
I was very pleased with the staff at the University of Colorado-Anschutz. Their knowledge, professional care, and follow-up are top notch.

If you want to talk with me more about it, feel free to contact me at miltdbrown@yahoo.com.

Thanks,

Milt Brown
Patients,

I received your letter requesting my experiences with my operation. I appreciate the opportunity to relate them to you. You wrote you think of us every day—I am also reminded of you each day. I have lived 10+ years that I wouldn’t have with my cancerous bladder.

There are some things I wish I had known before making the decision for a neobladder. I should have realized what the loss of my bladder muscles would be like. The statement made to me “everything will work the same” is not true. It seems both bowel and bladder respond to the same nerves. My bladder nerves seem to continually tell me I need to urinate, which I have to ignore.

Before the operation, for years, my bowels were consistent—once per day between 6 and 7 AM. My creatinine level was consistently below 1.0. My bowels are now irregular, often several times per day. My kegel muscles work pretty good during the day but are insufficient when I sleep. I have to get up twice per night to relieve my bladder. I have to do just as your assistant told me when I checked out of the hospital—wear diapers during sleep.

After the bladder operation, I developed excessive bile acid production and at the same time they suspected a plugged ureter. After 4-5 times trying to confirm the plugged ureter, they sent me to you. As I watched the screen during the test, I could see one ureter was plugged, not passing any of the chalk through it. However, it was reported to my doctor that neither was plugged. After that, no one in Cheyenne, WY would consider checking further. I lost 55lbs of weight and in desperation, I went to Mayo Clinic in Phoenix, where they unplugged the ureter and neutralized the excess bile acid. They told me in Phoenix that a neobladder for a 70-year-old was questionable.

About 3 months after my surgery, I experienced some blood in my urine and occasional pain in my bladder. My doctor went into the bladder and removed several crystals and some free staples that were moving around and irritating. I have had no more life problems since. My creatinine level has steadily climbed to the 3.5 – 4.0 range and once to 5.2. We continue to monitor it and I stay on sodium bicarbonate pills daily. Thus far, my cancer has not come back.

Sincerely,

Bill Solomon
Email: KRB1CARR@aol.com
I got the bag instead of having a pouch made. Pouches can cause more infection. I had to suffer with infections for many years prior. I was sick of doctors and I wanted what was easy, or so I thought.

I had my surgery in 2008 and I still have ups and downs. They try to teach you, but you won’t learn until you’re on your own trying and failing.

Because your kidneys are always working, it always has to be covered. I recommend not drinking anything until you change the bag so it is easier to get a good seal on your bag. Always clean the stoma with warm water (I use wash rags). Don’t be afraid to rub hard around the stoma. Not the stoma itself, but the skin around it. You have to get the resin from the last bag off. After, take a dry washrag and dry. Keeping it covered, I use a hair dryer on low and that helps it be extra dry. Once you have your bag prepared, keep dapping the stoma. When it sticks out, urine will probably be coming. Wait until it is kind of flat, then place the bag over the stoma. Keep your hand on the bad to keep the paste warm, so it seals. Again, I also use my hair dryer and warm the seal up quicker.

I started with the paste, but I couldn’t get a good seal. Now I use barrier rings which is like paste but it’s a ring you shape around the hole in the bag. Then just do the same as with the paste. Sometimes you will think it’s perfect, and an hour later it is leaking. I wear mine for a day before I feel more comfortable going anywhere. I change on the third day. Here are some things that may help:

- Pink tape for shower
- Half-moon tape strips that go around your bag for a stronger fit if your going to be active
- Wipes just to make sure nothing is on the skin when putting on the bag completely dry.

Good Luck.

Janice Seal
My name is Jeff Novotny.

This is a hard thing to talk about, but thanks to friends and family, I knew it was the best thing to do. After my surgery, I lost my balance for over a month and had diarrhea for about two months. Over a period of four months, I lost over 50 pounds and just didn’t have much of an appetite. I had to force myself to eat again and pick up my strength. It was a hard thing to do, but I had to.

About Dr. Wilson, she is a great surgeon and a wonderful person!! I had no doubt about her abilities as a surgeon. She told me that she does about 100 of these types of surgeries a year of, and that she has been doing it for ten years. All around, I think I had the best surgeon!

I think it was the nicest hospital I had ever stayed in. The staff in the I.C.U. on the 3rd floor took the best care of me! I went to the 11th floor next, where the staff was also wonderful. The hospital had the best food, when I actually felt like eating. The view of downtown Denver was beautiful. All around nicest people, a great hospital, and the best surgeon… I was in the best hands!
In preparation for a cystectomy, or any surgery, you must have confidence in the surgeon and the team. Dr. Shandra Wilson makes you feel that you are in excellent hands and will have the best possible result. I never felt a need to get another opinion. The fact that she does 75% of the cystectomy surgeries in the state is a tribute from the doctors of the state of Colorado and surrounding states to her skill level. If she didn’t have the patient rapport, skills and the outcomes that she does, she wouldn’t be performing 75% of the cases. The staff in her clinic and in the hospital tout her skill and compassion.

The post-operative recovery was longer and more difficult than I had anticipated. I was very weak for several weeks. My sex function will be a thing of the past, but I’m just be glad to be alive.

Depends may or may not become an essential items of apparel for you. If you need a little extra absorption material, I use the overnight pads in the Depends and cut them longitudinally about ½ the way from the top end. This allows for absorption into the Depends as well as the pad.

Jon McMillian
I was shocked and dismayed when the doctor told me I had to have my bladder and prostate removed. I had a relative who had a similar operation done many years before me. He smelled like urine all the time. I had always hoped that would never happen to me. Well it did. One of the important things that I learned was there is no odor if you follow the instructions from your ostomy nurse. The second thing I learned was it is easy to camouflage the appliance. My wife made some denim covers for me and I wear my shirt tails out. You get used to it and can do just about anything you did before, except maybe swimming or wrestling.

Here is the downside: the recovery is long and painful. For me, it was seven months. I was 79 at the time of the operation, so that may have been a contributing factor. You have to change the bag every three or four days, it takes about fifteen minutes to do so after a shower. The stoma doesn't have nerves so it is painless to the touch or if you bump it or something.

The constipation immediately after and beyond the hospital is a bitch. That was one of the worst things I experienced. One thing that really bothers me is when my prostate was removed, so was my desire for intimacy (Yes, even at 80 years). Fortunately, my loving wife has graciously accepted the fact we won't be intimate any more. My wife also helps me with the bag change, it is much easier than doing it in front of a mirror. You are going to have accidental leakage. I have had two embarrassing incidents and four or five other events. After a year and a half, I am very much aware of this potential and am careful not to create the opportunity. By that, I mean I am sure my waistband isn't cutting the bottom part of the bag off by being tight across the middle. When I am doing lots of bending like in yard work I check the bag to make sure the flow is not restricted. Once you cut that top off with you waist band it is only a matter of time before the pressure loosens the stick-um. I bought a stoma cover, but it was a waste of money. Every time I leaned forward it would cut the flow off to the bottom of the bag. I think these things are a racket, preying on us with unfilled promises.

Sincerely,

Marvin Cronberg
My name is Donald Bronson. I am 48-years-old now and I have a neobladder. I don't know if this will help any patients, but I will write what I have experienced. The first diagnosis of the cancer was obviously shocking to a level I have never experienced in my life. It feels like you are faced with a death penalty. I have four children - my youngest was 6-years-old at the time. I prayed to God that he let me fulfill my duty as a parent on earth and get me through this so my children and wife would not have to suffer further.

The first month to three months following surgery was like being in hell itself from pain and emotional pain.

The next year, and still to this day, is the challenge of managing pain that is associated with this procedure, urination, constipation, and mental depression. I now have symptoms of PTSD and they don't seem to be getting better - yet. The pain somedays is like a radiator heating up and expanding inside my abdominal area every time my new bladder seems to feel like it is full, but then I struggle to urinate for many minutes on the toilet, sometimes bearing down to no avail.

About six months after surgery I got a horrible infection and was hospitalized again for 5 or 6 days. I believe it was due to trying to work with a Texas catheter to prevent wetting myself all night.

It's been about one-and-a-half years now and I still need lots of medicine to manage my pain. I feel it immediately when they stop working and wear off, so having enough painkillers has been a struggle as the medical industry unfortunately frowns on painkillers. Some days it feels like a drill has been turned on and is drilling up from my penis to the middle abdominal area, always associated with the feeling of a urge to urinate, but it can burn many times as the plug of cells leaves my urethra. The funny thing is that many times it's just a few drips or me bearing down to create small squirts of urine leaving my body.

I have been to pelvic pain specialists, pelvic therapists, and physical therapy for many sessions - 8 or 10, I don't fully remember. I still use some of the techniques the Dr. of PT (Dr. Laura Krum) helped me with - she was excellent. I have had good days and bad days, or even weeks at a time, were I just lay there and struggle mentally and physically. I don't do PT anymore as It has not done much for me other than strengthen the muscles a little better around my groin and lower abdomen. I squirt pee out uncontrollable many times during the day if I stress any muscle too much around that area so I wear a diaper 24-7. I don't want to scare anybody. I consider it a miracle that I am still alive to see my family every day. That miracle is completely due to God and the excellent care Dr. Shandra Wilson created for me with her magic hands and her superior surgical skills.

My hardest times are at night and in the morning because I'm on testosterone therapy daily and I never sleep longer than five hours at a time. I mostly wake from the pain and from the wetting side effects of having no control of my penis leaking while I sleep. I go through 5 to 7 diapers every day. At night, my average sleep is about 2.5 hours at a time before my diaper is so wet or the pain has woken me. I continually struggle to get up and change my diapers every night many times, that has not changed at all. I don't believe it ever will as it has been a little over 1.5 years since my second surgery of the neobladder.
On a good note, I feel very blessed to have had the greatest surgeon in the world build my neobladder, Dr. Shandra Wilson and her caring assistant. I'm blessed to have a second chance on earth and incredibly blessed by not having an external bag on my body. I think that is a great thing and I try to focus on that positive aspect of all of this. My heart goes out to the greatest medical team at University of Colorado-Anschutz.

I have many medical expenses from this, and it has changed my financial situation permanently. My primary care doctor, James Boland, has also been incredible. He listens and does everything in his ability to reduce my suffering. I'm lucky because he was a former friend of mine for more than 25 years, so again, a very good part of all of my experience. I just hope a person who goes through this will have a friend like I was blessed to have.

Back to finances, it has been impossible to provide financially what I used to provide to my family. I love my wife dearly and without her, I would not have had the spirit to make it through this. Our intimate life has been destroyed for quite some time, as the needle injections into my penis were insufficient. I stopped those injections after three attempts. During one on them, my penis swelled up like a small rubber bouncing ball was stuck under the skin, which was one of the scariest things. The injections were also very painful. However, on a better note, I currently take Cialis and am able to function occasionally but not like I was before the surgery.

Be ready to go through countless diapers and extra padding. This will help your sleep duration a bit. Also make sure you have a good pharmacist that always has inventory available for pain medicine and the other medications you take. I believe I have used approximately 1800+ diapers so far.

I think it is a miracle or me to still be here. Even though I struggle every day, it's better than not being here with my beautiful family, that is for sure. I do wish and hope that my future sleep time can increase. If you're reading this, I wish you the best of luck and I want you to know that miracles do come. Again, I can't thank my healthcare specialists more than ever, and also thanks to my wonderful family. God Bless Dr. Wilson, Dr. Boland, other specialists, my family and of course the incredible new procedure they can offer you.

😊
My Bladder Cancer story

I was at Road America, a iconic auto race track in Elkhart Lake, Wisconsin. It was November 2009 and a cool but sunny day. I was co-driving in an endurance auto race in my Mini Cooper S. After an extended period behind the wheel, I was a little dehydrated and went to the men's room and passed blood! I then made one of the best decisions of my life and immediately called home for a doctor's appointment.

The following Monday, I was in the Doctor's office worried about all kind of things but not cancer. After numerous tests and a cystoscopy, I was sent on my way while they awaited test results. A few days later, the phone rang with the startling news that I had advanced bladder cancer. I was told in no uncertain terms, that I needed to have my bladder removed and faced no alternatives. A neobladder was the best possible outcome, but the possibility of chemotherapy, wearing a 'bag' for life, or even death was on the horizon.

I was stunned and immediately went into denial. I'll never forget having a second opinion appointment with Dr. Wilson a week later. I said, "I'm not going to do it, I'll take my chances," and that was that. She responded with: "then you will be dead in a year." It's hard to describe that feeling when the realization set in. I quickly came to my senses and made the second-best decision of my life. I scheduled surgery on Jan 11th which was only 14 days away. I went to 'sleep' that day not knowing the outcome. Fortunately, the cancer had not metastasized, and I was spared the extra trauma of Chemo, etc. A 90 Day healing process followed, and here I am, 7 years later, cancer free and continuing to enjoy life. The healing process was not easy but the light was there at the end of the tunnel as I got better and stronger each day.

I cannot emphasize enough how important attitude is. After the initial shock, I shook it off and decided I was not going to be another statistic. I'm very grateful to Dr. Wilson and the UCH staff for performing the miracle that has allowed me to share this. Since that fateful day in 2010, I have been blessed with seven grandchildren and a full and productive life. Sure, things aren't the same as they were, but I have no regrets. Life is full of lemons and sometimes you have to make lemonade.

Keeping a sense of humor is important too. Just before surgery, in my pre-op meeting with Dr. Wilson, I asked her to please save my removed bladder as I wanted to make a pair of Moccasins with it. She laughed, told me it wasn’t big enough, so we decided on a half a dozen key fobs instead. When I woke up, I was still chuckling and looking for those key fobs! A little laughter and a good attitude goes a long way toward making the healing process better.

The sky is always darkest before the dawn.

Randall Smalley
7 years and counting!
Dear future patients,

I am a lucky man. I was mugged on my way from the airport to my apartment in Washington, DC. I noticed blood in my urine when I got home, and my wife dragged me to my primary care physician. He was concerned and referred me to a urologist. The urologist performed an ultrasound that revealed tumors in my bladder. The urologist referred me to a doctor in the Urologic Cancer Clinic at the University of Colorado Hospital. I had no symptoms and, if I had not been mugged, the cancer could have spread unchecked.

My wife and I met with the doctor at the urologic clinic to discover facts concerning bladder cancer and to discuss my options. The doctor told us that my option was the traditional treatment plan that involved surgery and a catheter and a collection bag. While the plan might save my life, the thought of wearing a collection bag for the rest of my life was very troubling. We sought a second opinion from another surgeon in the clinic, Dr. Shandra Wilson.

I am a lucky man. We discussed the status of the progression of the cancer, the need to act quickly, and, most importantly, the additional options available to me. Dr. Wilson explained the surgical procedure that would result in a neobladder constructed from my intestinal tissue and the possibility that she could connect the neobladder in such a way that a catheter and collection bag would not be necessary, in other words, I could urinate in the normal way. We discussed the probability of success and failure and my wife and I decided under-go the surgery based on the information she provided to us and our confidence in Dr. Wilson. The surgery was successful and the outcome was as planned!!!

There are several things I learned from the experience, some are emotional and some are practical:

1. Cancer is scary but the saying “knowledge is power” is never more important than when it comes to making your own life and death decisions. Dr. Wilson answered all our questions in a compassionate, understandable manner. Knowing what to expect made me feel that I was in charge of my treatment and reduced my anxiety and the fear of the unknown.

2. The doctors, nurses and aids I encountered at the hospital always had my comfort and recovery at the top of their priorities. I experienced no negative instances during my six-week hospital stay.

3. I was discharged to a rehab facility in Lakewood. I had a gaping, five-inch-long surgical wound when discharged and the rehab staff were supposed the care for the wound. The facility was dirty and the staff was uncaring. One night, I spiked a fever of 105 and the charge nurse took twelve hours to notify anyone. I was taken to the hospital in an ambulance. While there, we discovered that the University of Colorado Hospital has a service that may refer patients to “acceptable” rehab facilities. We moved to another rehab facility with much better care. Had we used that service, I could have avoided the dangerous experience I had with the first rehab facility.

4. From a practical perspective, I worried about how my family could access the cash they would need if I were not around. I made a will and changed the names
on our accounts and vehicles from my wife and me to my wife or me to avoid the hassles of probate. I refinanced my house and sold some of our investments to create a cash reserve. I am a retired CPA and knowing my family had easy access to cash they needed for living expenses eliminated a significant source of stress.

5. I am a very lucky man. You may have noticed that I frequently mention my wife or we in this letter. My wife has been an equal partner in every step in this journey. I needed a caring someone to talk to about the fears related to the diagnosis, the surgery, the recovery and the quality of life after the recovery. She drove from Lakewood to the hospital every day to visit me. My surgical wound was not fully closed upon discharge from the rehab facility so she rented a hospital bed and created a rehab room in our house. Her compassion, intelligence and unwavering support are critical to my physical recovery and emotional wellbeing.

I hope this letter helps patients facing bladder cancer. Dr. Wilson is a world-class surgeon; the University of Colorado Hospital Urologic Cancer Clinic is a professional and friendly place and the Hospital itself is one of the best in the country.

Sincerely,

Michael L Beck
To all of Dr. Shandra Wilson’s other patients, and more so, those who are thinking of receiving the same operation as I did:

On April 5, 2014, I had a bladder “TRANSFER,” (I like to say “transfer” because my new bladder is (was) just another part of my body moved from one place to another place). When my urologist explained the type of surgery to me, not one second went by before I said one word: OK!

“Transplant?” From another human, a pig, or made from a monkey’s lips? Well maybe, as a last resort...

I am 75 years old and an amputee (49 years - lower right leg), so I do keep up with all news pertaining to transplants. There are many problems with transplants. Now, a type of anti-rejection medicine is linked a death, i.e. the first person to have a full face transplant - a woman in France. My “peg-leg” is OK in comparison.

I like to refer to Dr. Wilson as I do to myself. I owned and worked in Paint and “Body” shops all over the US for more than 45 years.

What’s the connection? (Drs. don’t like to hear it when I refer to the operating room as a body shop.) I’m sure that after all the surgeries that Dr. Wilson has performed, she has become her own worst critic, just as I was to myself. If the body work (or paint) didn’t suit me, the customer didn’t see it until later.

I would not be here today if it were not for Dr. Wilson. All the "body work" that Dr. Wilson performed on me in 2014-2015, I had my roof dressed up, new head-lights installed. Now, all I need to do is think of what color I’d like to be and go to a paint shop.

Colin Orf
Patients:

For years, I have used Nu-Hope custom made osteomy pouches. They have served me well until I recently experienced severe skin adhesion problems, resulting in almost immediate leakage. I routinely order 2-3 boxes of 10 pouches per box. I store them in a cool dry place. I always like to keep an extra 2 boxes in hand in case I need to make extended visit to my daughter in Europe. You cannot order or receive shipment of these boxes outside the US.

Currently, the FDA does NOT require osteomy pouches to label their product with expiration dates or storage recommendations. I carelessly received and stored these boxes with no receipt date on the box.

Following extreme frustration with leaking pouches, I contacted the CEO of Nu-Hope and sent him photos of unused bags showing uneven distribution of skin adhesive on the bags. SURPRISE... He informed me that these bags were over a year old from the photos and that is why they are not sticking to the skin. He is refusing to date stamp expiration dates (too much regulation and expense he told me).

So, I would advise patients receiving pouches from any company to mark the boxes with the date of receipt and use pouches within one year or perhaps sooner.

I hope this suggestion is useful for your efforts or at least can be passed on to anyone offering osteomy care to patients.

Best success with this endeavor.

Brenda Dempsey
1. Words of encouragement:
   - No matter how hard and bewildering it seems at first, an almost totally "normal" life will happen again.

2. What is the road to recovery look like? No need to sugar coat things, we want to hear it all!
   - When I considered the enormity of the surgery [almost 8 hours], the road to recovery was amazingly short.
   - The first day from the hospital I had NO PAIN and was able to climb stairs [to my wife's amazement].
   - Adjusting to the use of a catheter was a bit clumsy at first but you will adapt to using it.
   - That will happen within the first 3-6 months and will seem normal to use.

3. Insight from family members and friends on what it is like to be part of the support system:
   - I really did not tell my friends in detail about my catheter usage, as that is personal.
   - My wife, like me, has had to get used to it, and is no longer an issue.
   - Again, you adapt to using it and it becomes normal to you and your immediate family.
   - The only tip is to carry at least 2 catheters in a sandwich baggie with you go to work or anywhere where you will be away from home several hours.
   - I always have several extra in each glove compartment of all my cars. This storage saves you if you have forgotten your "baggie.”
   - I currently used bard brand, 12 coudee tip and get a 90-day supply from the vendor.
   - Most insurances will cover the cost of the catheters.

4. Things you would like to say about your medical team including the doctors, nurses, staff, etc.
   - Shandra Wilson, my doctor, is the greatest and kindest genius on the planet and I owe her for saving my life.
   - Her entire staff are cut from a similar cloth.
   - That kinda sums them up.

5. Any advice you have on the preparation for surgery or for when you return home afterwards
   - Prep: mellow down, your life is in the greatest hands both physically and spiritually.
   - After: You will say, “Wow! That was not so bad and thank God for my life back.”

You can email me anytime and we can share stories of our miracles.

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