

## Trench Talk - about muscle-invasive bladder cancer

Last Updated Friday, 14 November 2008

This page has been created in order to publicly share some questions and answers from our email discussion group on topics which may be of interest to those who are considering, or have had cystectomies as well as those dealing with invasive or advanced bladder cancer.

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[Experiences with Gemzar and Cisplatin\(GC\)](#)

My husband had neobladder surgery in August. Due to some spread to fatty tissue (but not to lymph nodes or other organs)he decided to follow up with a round of chemo. Our oncologist (Dr. Ronald Goldberg, Summitt Cancer Care, Savannah, GA) recommended a six month course of cisplatin and gemzar.

My husband would have both drugs for what we called the "big" treatment followed a week later by just gemzar - the "little" treatment. This cycle was repeated six times on a 28 day schedule - essentially 6 months. During the big treatment he would first be hydrated with a drip of fluids, would receive an anti-nausea drug and a diuretic drug. Due to the neobladder he would have a catheter during the big treatment. He went to our surgeon's office where they have a continence nurse who would insert the catheter. He would remove it himself the day after treatment. The catheter was protective of the neobladder - to keep chemo drugs from lingering/damaging the neobladder and kidneys.

During the surgery part of our experience, my husband was having some trouble with veins. After a lot of repeated sticks he decided that it would be best for him to have a port installed for the chemo. That was done as an outpatient procedure immediately prior to the start of chemo. I mention this just in case it is appropriate to your situation.

My husband did exceptionally well on chemo. It was not the nightmare we feared. His first time was the roughest. He never got ill to the point of vomiting, but felt generally flu-like. Initially, he lost his appetite and lost 5 pounds over the period of a week. He was given an appetite stimulant that was only needed for a brief period of time. He ALWAYS took his anti nausea meds for the first couple of days after the big treatment. Our doc stressed taking them before you really need them, because once you get sick it is harder to get it under control.

His blood was checked prior to each treatment and once again during the "off" period. If his white cell count was low then he received a shot to help bring his count up. We were extremely fortunate that his treatments were never delayed. Our doc told us, though, that a small delay would be expected from time to time and would not be a problem. He also told us that the treatment would last from 4-6 months, dependent on his tolerance of the drugs, and that a four month treatment would be acceptable. I mention this just so you'll know that there can be variation and that it isn't something to freak out about. Your case is unique to you.

Staying hydrated is CRITICAL so drink up a couple of days before each treatment and for a couple of days after.

It has not been an easy time, but neither has it been anywhere near the ordeal we anticipated. Be kind to yourself - be patient - you WILL get through it.

Best wishes to you. Please holler if I can be of any help. Katherine

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I just read what you said about not being to the place mentally to do the chemo yet and my heart went out to you. It is hard to walk into a place and smile while saying feed me poison and make me better, but that is what we have to do. You have to endure knowing that if you do you will come out the other end the winner and believe that with all your heart. You have to be so tired already this soon after surgery and the emotional roller coaster you have to be on. But I can tell you are a survivor and you will get into battle mode because you are doing what you have to do. I think one thing that helped me was getting a chemo pack ready. It consisted of things I would need to have to be at home during chemo. Cisplatin is a long chemo because of the hydration cycle due to the potential of harm to the kidneys as you already know. Movies for the DVD, books, booties, my mp3 player, a throw to be warm and that was fuzzy and comforting, a pack of cards, chap stick, lotion, my laptop went with me as they had internet hook up and I was able to email with my friends and on and on. I think every item I put in it brought me nearer to being ready mentally, in an odd way it gave me a concrete way of dealing. As if packing it was a way of saying ok I am ready to start this journey to wellness. I finished systemic Gencitabine/Paclitaxel/Cisplatin in May of last year. I did a two week on one off for four months. I had done twelve sessions with Paclitaxel/Cisplatin at a lower level in the fall before during radiation. I am not the queen of chemo thank god but here are a few things that helped me go into battle with the beast as ready as I could get.

The one thing I know about Cisplatin is that the thing you will have to do is drink liquids like you have never before. And it does not all have to be water juice, soup, or anything with liquid in it will do but do it you must. Especially for the days following chemo.

Pay attention to the small things I was so tired I had trouble getting out of bed and I did not call to report it and it was a magnesium deficiency that almost did me in. I thought I was being tough I was being silly. Don't feel as if you are complaining but that you are communicating to your team.

Get ahead of the nausea before it starts there are great medications take them as a prop lactic. If you like I could get you the schedule they use a where I went it did work well. And you could talk about it with your team. But I imagine they have their own.

Always keep something like crackers on hand never let your stomach get empty that is the beginning of the end with the nausea game.

Expect that some things will smell awful to you during your chemo and that some foods you like will not be something you want at all. I can not drink soda pop to this day and had always loved it until I started chemo. Find things that sound good to you and make sure you keep them around. Avoiding spicy and greasy is a good idea until you know how it will set with you.

Talk to your health care team about any vitamins, herbals or supplements that you are on. Some could have the potential to alter how the chemo interacts with your body.

Get Biotien mouth wash and toothpaste they help if you get mouth sores and if used from the first may stop that from happening all together.

My skin got incredibly dry so a good moisturizer is something I had with me all the time. It is a good time to start taking very good care of your skin. So I got the whole works and started giving myself facials.

If you experience and tingling in your fingers or toes let your team know right away.

Keep a log of any things you experience. They may be nothing but may be something they need to know about. Chemo problems often times are a thing of nuance. But can develop into more.

Baby yourself rest as often as you can. Don't worry about others problems this is a chance to be completely self centered and not feel bad about it. The only thing while going through systemic chemo that you should worry about is taking care of your mental and physical needs. We are often so used to taking care of everyone else that it is hard to let go of that. But you must give yourself time and strength to heal during this journey to wellness that is about to begin.

Only associate with people that are good for you right now and support you. One of the bennys about all this is you can get away with saying I would love to talk but am just to tired; use it as it does not last and Aunt Clara will expect your attention when this is behind you lol.

Push the stressors away they will still be there when you are done with this. You have the perfect excuse and right now the only thing you should worry about is making a cocoon for yourself in order to allow the chemo to do its work. And a calm centered place to keep balance is important.

I bought meditation music and a set of eclectic wind chimes as well as an indoor water fountain. I only watched things on TV that I could either laugh at or gain inspiration from. I went to Barnes and Noble on the web and ordered many of the books I had always wanted to read and signed up for a Barnes and Noble University course I had always wanted to take they are free. Done online and self paced.

I invested in the bedding I had always wanted a new mattress down pillows and 1000 count Egyptian cotton sheets. As well as soft throw pillows. My bedroom became a haven. My husband and kids helped me move a TV and my electronics to my bedroom. All with remote control.

If you feel like going out and can afford it have a facial, massage or a manacure there will never be a better time to pamper yourself.

Get someone to do the house work while you are at chemo if you can and cook a meal of something that will sound good to you. This lets you come home to a clean bed with nothing to do but rest and relax.

I went out and bought a few things that where nothing but comfortable. Robs and caftans made of soft fabrics that I could wear awake or asleep. As well as comfy slippers.

I spent at least a few minutes a day on the treadmill if I could. I believe that helped me a lot in keeping my strength up.

I took up writing and painting again I was able to let myself have time for them for time in years they worked for me as a sort of therapy.

I am sure that others have things that helped them get ready for the journey to wellness you are about to take and that they will share them with you. I hope these help in some small way. Know that you are on my mind and heart and that like me many people care about you and look forward to seeing you cross the finish line to wellness at the end of this journey.

I was given a prayer lovley shaw when I was starting chemo. At a local church a group of ladies get together and pray as they make these shaws they are big enough to cover your legs or wear around your shoulders. There is something about it maybe I knew that it was made with love and careing but I kept it with me throughout my chemo. If you would like it I will have it cleaned and send it to you. And when you no longer need it we will send it to the next soul who needs a little more love around them. If you would like that email me off line and I will get it in the mail to you.

Chin up and straight ahead

Cyndi

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### Our Chemo Experience

Several people have posted lately asking about chemo - as I did when we first learned that Dave would be receiving it. I feel his doctors have done an admirable job of controlling the side effects and making the process much more tolerable. He is currently over half way through a 4 month cycle with Cisplatin and Gemcitabine. Double dose day is the kicker with Cisplatin the worst culprit and he was very sick to his stomach last time.

Yesterday was another but the doctor suggested he double up on the Dexasone (4mg) and Zofran (8mg) and he pretty much sailed through the day. He also put a Lorazepam (.5 mg) under his tongue before the nurse inserted the IV and this helped 100% in making that job easier for both of them. He has

Apo-Metoclop (10 mg) to take every 8 hours or as needed but doesn't use it regularly at all between sessions.

I wouldn't say that chemo is a picnic but getting the nausea under control has improved the quality of life factor for both of us. He says pretty much

everything tastes of aluminum but has been eating nonetheless. Food with the least amount of additives seems to taste better so sausage and other processed meats are off the list.

His hands shake most of the time and it takes about two days after Cisplatin for his legs to stop aching. He is able to putter around outside, pretty much in 15 or 20 minute spells and then rests for about the same. He's got the place trimmed and tidied to park-like standards and has become an expert on the daily doings of all the local birds. This regimen seems to be good for his soul too.

The food aversions so frequently mentioned in chemo discussions are our experience as well. Won't touch asparagus or carrots. The smell of coffee brewing makes him sick. Doesn't like mixtures - stew or spaghetti sauce. I've been cooking dead plain with just one or two seasonings at a time and that seems to work. He's off salad (mixture) and I've got three rows of ingredients growing in the garden so have been hiding greens in stir fries and getting away with it.

Anyway, I would not be as fearful of chemo today as I was two months ago. He has had no appreciable hair loss either - a tender spot for many. Hope this helps others with accepting the benefits offered by chemo.

Carol

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Hi Carol,

I just finished chemo on the 23rd of May. When I walked out of infusion it was my 20th trip there. I was on Gemciabine/Placlitaxel and Cisplatin.

When I first started I was also scared to death you hear such horror stories. But to tell you the truth it wasn't near as bad as I had thought it would be. I had a great team in Oncology and they have gotten so great at handling the side effects. A

tip I will pass along is to never let your stomach get empty always have a little something around crackers where my best friend.

To add to what has been said about your tastes changing. With me it wasn't taste during my first round it was my sense of smell. It was a good and bad thing. I could smell things I never had before even noticed. At times it was hard to walk past a restaurant and at times getting on a elevator was a experience. For about a week I had trouble getting close to people for it smelt like no one bathed. But it faded away with time.

Finally keep in touch with your Oncology, ask them what to watch for and what to be concerned about. Do not let things go because you don't want to bother someone. They are very good now at adjusting medication if need be to keep the side affects down so don't suffer in silence.

I hope you get through as well as I have. And remember that few things in life are as bad as we think they will be.

God bless

Cyndi

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Hi Carol...

It's strange how almost all of us have the same symptoms with the cisplatin on this list. One of the weirdest things that happened to me is my hatred for turkey sandwiches that I developed. I used to LOVE turkey in any way, shape or form, mostly in a sandwich but I haven't touched one since April when chemo ended! Strange, huh? I just can't get my stomach up for it.

I hope your husband is doing better and is tolerating this better every time I have to start again on the 21st with Gemzar/cisplatin again. Ugh! But it s not the worst thing I've ever done!

Take good care,

Jane

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Hello all: I have mentioned in previous chemo discussions that my food aversions were similar to morning sickness I had with my 3 pregnancies: sudden aversions to things I normally like such as coffee, green veggies, and my usual white wine tasted like turpentine. I was on the cisplatin and gemcitabine cocktail for 4 rounds (8 treatments). Cisplatin days were the worst as far as the nausea goes. But the only time I actually got sick to my stomach was the day after the first treatment.

The anti nausea drugs didn't totally make the icky feelings go away--on day 3 I usually had insomnia and constipation from them too. Once I was done with the chemo, my taste buds were about the first thing to return. It took longer for the hair I lost (half of it) to come back in. And to this day I will never order a chicken salad sandwich in the hospital cafeteria as I would gag at the sight of it--I can eat that any place else. By now it's a totally "mental" thing when it comes to the food I had during chemo treatments. (I had them Jan through April 2002).

Nancy

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#### Chronic Urinary Tract infections following bladder removal

I am a 69 year old male. During the Summer of 1999 I had a TUR followed by BCG Chemotherapy (once/week for 6 weeks) followed by a second TUR. BCG was found to be ineffective. Surgery was performed on November 3, 1999 to remove bladder, prostate, and lymph nodes. A neobladder was constructed from a section of my intestines. Since that time everything has gone very well with one major exception. I have been plagued with what I would refer to as chronic UTI's. Each episode begins with a fever, followed by a quick trip to my Urologist who puts me on antibiotics (Cipro - 10 days, or more recently Levaquin). At one stage during the past two + years, my urologist had me on Gentamicin Irrigation solution that I used daily for 6 months when I irrigated my bladder. As long as I am on any one of those treatments everything seems to be just fine. When I last calculated, I had been on antibiotics 47% of the time since my initial surgery. That concerns me. At any rate, I have just gone off my last treatment of Levaquin following my latest UTI and am fearful that another UTI will appear shortly. Finally, I am new at using the internet to research this problem. I find lots of info. regarding diagnosis & treatment options for bladder cancer but little info regarding post-operative treatment for my UTI's. Can you help? Any thoughts regarding alternative protocols for treating UTI's? Any suggestions about sources of information? I would appreciate any help you might provide. Thank you very much. R

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I assume that he has has many, many cultures done to identify the bacteria causing his infections? Without multiple cultures (should do one each time), any antibiotic choice is simply a shot in the dark.

Also, if he is cathing, ect....really really be precise about sterility control. I would use a sealed, new disposable catheter each time for a good long while, along with new gloves. You cannot be too careful once you start getting UTIs.

Trauma can also be a contributor to multiple UTIs. Make sure he is cathing correctly and not too often.

Same advice women always get, including no baths!! Change everything...type of underwear, pads, diapers (if used).

Is he voiding completely? Ask a nurse about how to make sure.



Of course, cytology and other tests to make certain that is an infection and only an infection.

I know from personal experience, that once you have had several, they climb right to the kidneys before you notice...and then the fevers, nausea, ect.

Being on antibiotics that long is not a bad thing. They used to recommend one bactrim (sulpha) a day to head them off. Now out of fashion (for good reasons), but bacteria can lurk in a nice warm environment for a long time!

sherry

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Is he cathing regularly? IF so maybe his technique needs to change. Also, ask him to add cranberry extract capsules to his regular daily regimen. They are available at health food stores and have proven antibacterial effects. My pouch is nearly two years and i have had only 2 UTIs since. I credit that to good cath technique [clean rather than sterile as I reuse catheters and wash a lot, and use an antibacterial lube], and the cranberry extract capsule[s] daily. I also take 1000mg of vitamin C. Karen

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Is he cathing at all with the neobladder? Some have to cath daily and if

so, this could be one cause. Had an IVP or CT or MRI to ensure there are no leaks, fistulas? Kathy

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Since I cath my neobladder all the time, I had 14 UTIs within 12 months, so my uro prescribed 100mg of Macrobid to take each day at bedtime. After taking Macrobid for a year, my uro has now told me to stop to see if infections recur. I stopped the daily Macrobid just one week ago, so it is too soon to know if the UTIs will recur. Perhaps his uro would prescribe Macrobid. Most of the antibiotic goes to the neobladder, and that is why it is taken at bedtime. I had no side effects at all.

"Neobladder Woman--Anonymous"

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Regarding the man who has been on antibiotics so much, my only suggestion is that he needs to find a different (hopefully better) doctor. From a strictly layman's guess, it sounds like a problem ultimately from the surgery, and somebody needs to go back in and have a look. Needs a real expert at the very top of the field. (My suggestion is M.D. Anderson or Memorial Sloan Kettering, but that is my answer for everything.)

AM

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Does he ever have to cath due and/or does he have any problem not completely emptying the neobladder? Either can lead to infections. I have been really lucky and have never had an infection in the 7+ years I have had my neobladder, but I do not have any problems so far with residual urine and never have had to cath. Chris

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Pouch Irrigation

Hi to all,

Karen stated that the Indiana Pouch is to be irrigated once a day. I'm 11 weeks post-op with an Indiana Pouch and to my knowledge was never told to irrigate it. My two questions are why irrigate and how do you do it? Dimity

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I irrigate with a saline solution once per day (or more if mucous build up) through the catheter (the same cath's I use to void) directly into the pouch using 60 cc's of saline solution and a tumi syringe. Many pouchers use a 'turkey baster' (see pouch).

The reason we irrigate is to flush the pouch to minimize the build-up of mucus so urine continues to drain freely, help prevent the formation of stones, and help prevent infection. If you go the the link I provided, you'll get a complete overview of the care and feeding of an Indiana pouch. If you are 11 weeks post op and you are intubating to void the

pouch, you should be irrigating. It seems to be the one standard across the board for pouchers, please check with your medical professional before venturing on your own, there may a reason why your physician does not have you irrigating at this time.

Kathy L

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The pouch puts out a lot of mucus-- which you see if you void into a urinal or use a clear catheter-- makes the urine look like egg drop soup. Irrigation is done to rinse out excess mucus from the reservoir-- which is made from bowel tissue [which normally excretes mucus to help the fecal matter move along smoothly. There is a lot of individual difference here-- some people never have a problem with it, others regularly get clogged catheters and slow voiding because the urine is thick. Some folks on the list never irrigate but drink plenty of fluid 2+ liters per day, etc. You do it through the catheter after you finish voiding. Use saline which you can get by prescription or make it yourself-- 2 tsp salt per liter of boiled water-- cool it first before using. With a syringe, slowly insert 60cc of saline, and let it flow out of the catheter again or add more until it does. The urine should run clear etc. I was told to do it by my doctor, and so I do, not always daily, but at least several times per week now. Karen

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### Serious Leakage Problems/Tips

I am 54 years old. In Sept of 2000 I had a cystectomy after fighting bladder cancer for 5 years. The wound was very large, the operation took 17 hours and I have been making slow recovery of the wound. I received an indiana pouch with a stoma through the navel. Recently I have begun to leak profusely (6 or 7 times a day) in large amounts. Even though I have increased my catherization and am getting only 200-250 cc out the leakage has been almost explosive and I don't know what to do. It has resulted in my refusing to go to work or outside the house because I can never predict when this is going to happen. If there is anybody who has experienced the same and has been able to have the problem corrected I would welcome your help.

Thank you, Michael

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Dear Michael, I have had a number of episodes of profuse leakage, once wetting so badly in the car my clothes were drenched out to my coat. I often have times where I will have a little burp of urine, usually contained by my sanitary napkin stoma cover, sometimes a bit more, but it takes a while to achieve full continence. Perhaps bowel motility is pressing on the reservoir. What does your doctor say? One thing that can be done until the crisis is over, is having a balloon catheter inserted to remain resident in the reservoir, and then wearing a leg bag under your clothes for a while. While it may feel like your regressing back to those surgical days, it will help you get over the hump until the reason your reservoir is so active is sorted out. Karen

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Michael, This spewing and regurgitating of the pouch happens to most, if not all pouchers, and as you are only a few months post-op, this could be part of the newness. However, Karen is right, please check with your doctor. I can give you a few pointers that I learned from my doctor and the more experienced pouchers. Do know that it can take as much as up to one year to become continent. I rarely have any leakage and haven't used any type of covering on the stoma for a year. Be patient with your body, recovery has to happen from the inside out, emotionally, too. It will take your reconstructed bowel sometime to "learn" its new job, so it may produce a lot of mucous for a while and it may "go native" and act like an intestine sometimes. Again, Michael, call your doctor first to ensure there isn't a physiological problem or infection. Now, here's what has worked for me and many others:

If the pouch is spewing uncontrollably, try intubating with your saline solution more frequently...could be a mucous plug or buildup that is forcing the pouch to squeeze urine out of the stoma.

Another helpful hint was to chew two imodium AD tablets (I confirmed this idea with my urologist) to calm the other bowels that may be pushing against or resting near the pouch...this really works for me.

The last thing that may cause the pouch to misbehave is a mild infection, or "pouchitis". This can be determined by your doctor. I hope you go to your doctor first thing Monday morning. Best Kathy L

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Lifestyle Questions

I had the IVP, surgery on Dec 15 to remove numerous tumors which turned out to be T2 grade 3 and am scheduled to have my bladder removed the 23rd of January. I am 48 years old and everyone giving me advise thinks I should have the Indiana pouch. I am concerned about the maintenance and leakage I've been reading about. I would like to continue in my normal lifestyle and travel monthly on business. How much leakage did you and the rest of you pouch people have? Would this be something that could easily be contained when I travel and work? Would I be able to contain it with a bandage? How much absorption did you need to provide for? Is leakage a constant problem or something you deal with only as you are adjusting to the pouch? The idea of having a bag attached to me doesn't appeal to me except that it seems like it would be less difficult to manage and more convenient when I am traveling. I would appreciate your comments as I make this important decision. Thanks, LaNette

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Dear LaNette,

This is an important decision for you, so I hope that I and others can impart some wisdom. I have an Indiana Pouch and travel for business, I am two years post op, and as of today am 99% continent. I rarely use any protective covering, and then it's only a large telfa pad to catch a mucous ball hiccup. That's not to say I didn't experience the leakage early on, I had several mishaps the first six months as the pouch was learning it's new role as a reservoir, this is very common, but believe me, it will go away. The leaking can be contained with the proper protection...(Karen and I could share our first experiences with a pouch that went native). Let's say, I've never been embarrassed, nor was I unable to contain the eruption quickly.

Each experience is as unique as we are. Bottom line for me, leaking is not a constant problem and as Karen has said, we carry a catheter and some lube, that's it. I have never regretted my decision. I advise you to weigh all the pros and cons and talk with as many of us as you can to get a broad view of the pros and cons of having an indiana pouch or an external appliance. My urologist is also my surgeon and was trained to perform the pouch surgery, ensure your surgeon is as skilled and experienced. I chose the pouch because of my age at diagnosis (47), lifestyle, talking with my uncle who has had an external appliance, and believe it or not, I really, really wanted to sleep on my stomach and thought it would be a struggle with an external appliance.

Best, Kathy L.

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Dear LaNette,

I agree with Kathy. You need to talk to as many people as possible. I am very happy with having chosen the pouch. I was concerned about skin problems with having something glued to my side, as well as just the idea of wearing a bag all the time. I wear a half sanitary napkin over the stoma and that is enough to catch any "burp" of urine or mucus. I have also used a 1/2 Poise pad which is specifically made for incontinence. I have not had a problem except for once when I think I must have had a lot of bowel motility and my pouch leaked copiously at a time when I was driving and could not stop to cath. I am fully back in my life in terms of recovery and the pouch has not gotten in the way at all. I even cathed at 40,000 feet on the way to Florida in October. I have not found it has gotten in the way of work or travel at all. I sound like a 2-3

year old, talking about toilet training. However, I find I am going longer between voidings at night than during the day-- for example, I go at 11:30pm and find that I am waking up at about 5:30 to void. That feels like a night's sleep. And I usually do not wear anything [on the stoma] at night. During the day I am up to 2-3 hours. Others on the list go longer between voiding. The only other maintenance, other than having a catheter on your person at ALL times, is irrigation. See Kathy's info on irrigation on the site pouch. Feel free to ask any other questions-- on or off list. The surgery is longer and harder since they are rearranging a lot of plumbing, but, worth it.

Good luck, Karen

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Tom, I am gearing up for the cystectomy next month. I would like to hear of your experiences, especially the period after the operation - days and weeks of recovery. I am an avid cyclist and look forward to riding a "Century" this fall. Is 6 mos. enough to regain what I need to do 7 hours of cycling? .Jeff

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Hi, Jeff!

I am glad you contacted me. Let me put your mind at ease. 6 months may be pushing it a little. I told my wife I would probably be restricted from running for 6 months after surgery, but to my surprise, when we met with him in October (4 months after surgery), and he told me I was free to do anything I wanted, I asked him about running. He said, "you can do anything you want, until it hurts, then quit". So, I started running again. A little at a time. It took a good month to really feel good again, but I wasn't going very far each time I ran (up to 4-5 miles if I remember right). Cycling should be a little less stressful, however, so perhaps you can get back into shape a little quicker. I was off work 5 weeks (I was in the hospital 12 days during that time, however). I found I had no energy at first: I could not take a shower, and then shave, like I normally did. I had to rest in between. It took a good 2 weeks to get some stamina back, but I still tried to nap during the afternoon, and get a good nights sleep (which is hard to do, since in retraining the bladder you can only go so long each night before you get up and go to the bathroom). In retraining the bladder, the doctor had be go 2 hours between going to the bathroom, around the clock, the first week. The 2nd week, it was 2 hours during the day and 3 hours at night. The 3rd week, it was 3 hours around the clock. The 4th week, it was 3 hours during the day and 4 hours at night. The 5th week, it was 4 hours around the clock. I was to continue this until I was at every 6 hours around the clock, but I never made it. 4 hours was about all my sphincter muscle could hold. Now, however, I have gone 6-7 hours some days, depending on how much I have drank, and how much my body needed (especially after a long run, for example).

I hope these experiences will help you. Each person is different, and each person's surgery's results are different. But hopefully you will make as quick, and as complete, a recovery as I have. Good luck, and may God watch over you, and your surgeon. Tom S

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## Sex after cystectomy? Male

Dear Roni,

My husband (age 62) had radical cysectomy 10/13/00 at U of M (Dr. Montie). He has a neobladder and is managing very well. He uses about one pad per day and perhaps two at night - sometimes none. Everything is going along fine - EXCEPT - he is impotent now. Never had any problem at all prior to surgery. I note that you have information relative to alternatives to impotence. I would appreciate any information you can give us. I am rather shy about asking the "group" for this type of information, but would like to know more. We had a very satisfying active sex life prior to this and while we are thankful that he has survived thus far and if an active sex life is a trade off for his life, so be it; but, if there are alternatives, that would be helpful.

Thank you for whatever help you can send our way. R's wife

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If you haven't already done so, check with Dr. Montie to see if he did

nerve-sparing surgery. If so, it can take several months (even longer in

come cases) for the nerves to start working again. In some cases, Viagra or Muse may be necessary. If nerve sparing was not possible, then Viagra or Muse won't work, and then one of the alternatives may be helpful.

Ben has had a 3 piece inflatable prosthesis since 1985. It is comfortable, unobtrusive and works great. The following quote is from "A Guide to Bladder Cancer, Urostomy and Impotence" which has two chapters on Impotence and Protheses:

"Happily we can report that the inflatable implant has enabled us to resume our sexual activities with all the vigor and pleasure we enjoyed in the past. Actually, aside from the vagaries of the normal aging process, very little has changed. The normal, pleasurable feeling of tumescence of the penis is gone, there is no ejaculate or natural lubrication, and it does take a few seconds to inflate the cylinders. On the plus side, however, there is the ability to sustain an erection as long as desired, whether twenty minutes or two hours. The benefits of this should be obvious to anyone who has ever had a performance problem or wished for a few minutes more. Furthermore, sensations are little changed in intensity or pleasure, and all worry of failure to perform is eliminated. Impotent patients who have enjoyed a normal vigorous sex life in the past and are considering a similar implant, whether after radical pelvic surgery or any of the many other reasons for physical impotence, should confidently expect similar results."

For a longer excerpt go here: [Impotence](#)

The inflatable prostheses are comfortable, unobtrusive and work great. The semi-rigid rod prosthesis are uncomfortable, obtrusive and don't work too well.

It is very important to have a surgeon who has a lot of experience! In many cases, it is possible to have the reservoir and pump for the 3 piece prosthesis inserted during radical cystectomy (RC). The reservoir goes in the abdominal cavity and the pump in the scrotum. This allows the scrotum to heal along with the RC. The cylinders can be inserted and connected to the pump and reservoir at a later date, or they can remain unconnected without causing a problem. This is done through a small incision near the base of the penis and generally requires anesthesia, an overnight stay in the hospital and a lot of ice.

Ben's pump and reservoir were inserted during RC. Six months later the cylinders were inserted - overnight stay in the hospital and sore for about 6 weeks.

Also, a lot of men and their partners are very satisfied with results using penile injections (PEP and Caverjet). Even though they say the injection isn't painful, it didn't sound appealing to us. Also, one major drawback to PEP is that it may cause an extended and painful erection. Although this is rare, the individual has to go to the ER to relieve the problem.

Over the years, we've heard just about everything and are comfortable talking about everything. Don't hesitate to email or phone if you think we can help. Best, Roni ROlsen64@aol.com

\*\*\*\*\*

From what I have received so far, soy is the big thing. We also started on an immune booster. As for the impotence. That is a worry for us also, but like you say, if its life or sex, we'll choose life. Actually, Dr Wilson, our surgeon, brought up the subject for us. He said he is generally able to save the nerves, but just in case something happens and he damages them, he will be prepared to place an implant during that surgery and Larry will still enjoy the sex. I know what a problem it is when it's gone, 2 years ago I had a ceasarian (yes at our age we have a 2 yr old)-6 weeks no sex. OUCH, and we haven't been able to have it since his TUR 2 1/2 weeks ago, again OUCH.

There are also other options besides the implant. My father had prostate cancer and impants were not available then, he has injections that he gives himself (In the penis area) to "get it up". Your urologist should be able to give you all of the options, I know there are more out there. Let me know if you find a solution for ya'll. Don't be embarassed to talk to the list about it, I'm sure it is a problem many of them have gone thru and can help with. Also, don't be embarassed to talk to your doctor, he/she has heard it all and has answers.

Good Luck, D and L

\*\*\*\*\*



Dear D and L,

Welcome to the group. We are new this year also. Frank had his bladder removed on Jan. 26, 2001. The doctor did try to spare

nerves and didn't say anything about implants. I would like to know more about this. He did say that it takes a while to recover any positive

response. Maybe three months. But i was talking to a friend whose husband had his prostate removed and was out of action for a year. So i guess us wives have to patient. If we act to anxious about it, it may actually puttoo much stress on the subject to get action. As with all the other aspects of this problem, we learn to take one day at a time and be glad we have it. C

\*\*\*\*\*

To R's Wife...I had my cystoprostatectomy on Oct 26th 2000. My

doctor thought that the procedure had gone very well and advised me to wait and see for three months. After three months and still no sexual awakening he advised I try viagra. I did, it worked. It wasn't all that I'd hoped it would be but the rewards of having this part of our lives back has been ablessing for me and my wife. We've been married 30 years this year, I am 50. I wish you both well, and like you say, you're already ahead on the trade off. Keep up your faith and good thoughts....Ed

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[Sex After Cystectomy Female](#)

Hi all,

Now that I have gotten your attention...

All you post-cystectomy/post-protatectomy guys have been so open talking about what bedroom worries you have had, and what surgical and other remedies have helped. I thought I would bring up something which we have not discussed

on the list but which affects those of us [and those who love us] who have had cystectomies-- but who also used to have uteri and ovaries.

Before the surgery, my doctor informed me that the standard procedure is to do the total hysterectomy [which was almost harder to get used to since I was sort of attached to my generative organs, and I had been prepared for the loss of the bladder], and also to remove the top third of the vagina. In worrying about the surgery I did not really think about the implications. Once I could finally take my new vagina out for a test drive [8 weeks after the surgery] I found that it is very hard to have sex with half the length I used to have! I was assured that things would "stretch" with regular exercise, but my poor husband is feeling like an abused Roman battering ram.

I wonder what the rest of you out there are doing to help the situation--

and how long does it take to get back to having riotous sex without

thinking of it as physiotherapy!

K

\*\*\*\*\*

Hi K

I had a hyst 3 yrs before the cancer hit my bladder (remember me, I'm the one with the rare uterine sarcoma not BC). the tumor was discovered by my gyn during a regular checkup. He could feel a nodule on the wall of my vagina. He biopsied and found it was recurrent cancer. The surgery that I had was called a Pelvic Exenteration. My bladder was removed and replaced with a neobladder from my upper colon. My vagina was completely removed and replaced with part of my stomach. A large section of my bowel was also removed because of radiation damage.

I must confess I was shocked that we could resume sex 6 wks after surgery. I thought it would take longer. I have not had any problem, I guess because my stomach replaced the vagina. I wonder if it makes a difference because a gyn onc surgeon did the surgery, not a urologist. I do know that while I was having radiation, the rad doc always told to continue having sex as the vagina would shrink. She measured me every time I saw her. Have you been measured? Are you stretching?

I don't know if any of this is of any help to you, but I will be praying you

and your husband get some relief soon.

M

8 yr leiomyosarcoma survivor

\*\*\*\*\*

Hi M,

Yes I am stretching-- we are having intercourse, but it is rough on my husband since he hits the back wall soon. I also just bought a tiger striped dildo [stripes not required] which is long and narrow, as I do not need to stretch in the width. I have to get into the habit of doing it daily. K

\*\*\*\*\*

When I found out that I would have to have to total hysterectomy as part of the cystectomy, the first question I asked my surgeon was whether I would have any sexual feeling afterward. She said, of course, all the peripheral and external structures remain, the clitoris, labia and lubricating glands. While the vaginal barrel is still shorter than it was, and requires some creativity, I remain orgasmic and even enthusiastic. Being alive does a lot for my sex life! K

\*\*\*\*\*

K, thank God someone finally brought up this issue . I had the same surgery as you June 98 my husband and I have only attempted sex twice since then its so painful, and I have just about given up talking to docs about it. I have been told it's an image thing and will get better in time, to do the stretching thing which you mentioned. The doc talked to me about Viagra but I dont feel there are enough studyies done on woman at this time. Meanwhile I thankgod for my wonderfull patient loving husband, I would love some input on this subject from other pouch ladies and thank you all for being there. J

\*\*\*\*\*

I had 3/4 of my viginia out and remolded with some intestines, then they gave me a dilator that I had to wear all the time for 6 months. That was really uncomfortable. My husband was great about it , It was a long process but once I was able to get on hormones it got easer and now we have a good sex life. D

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Hi there, Thanks for sharing about the dilation process. I have not seen a dilator that one could wear all the time. K

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