

Ask the Nurse

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Sharon McMullen, RN, CCRN, BSN, BA is a critical care nurse working in Philadelphia, Pennsylvania, USA with professional experience ranging from general surgical nursing to critical care nursing to emergency nursing. She will be glad to help you translate medical jargon, read between the lines of your medical records, or just navigate the often confusing world of health care.

Sharon's corner is now closed to questions.

What kind of hospital stay can you expect before, during, and after your radical cystectomy and urinary diversion? Nurse Sharon McMullen has written an informative page for WebCafe, 'Hospitalization for a Radical Cystectomy and Diversion'. [Click here for the article.](#)

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Sharon's story

My Mom was diagnosed with bladder cancer on December 22, 1998. A few weeks later, I became active in an online bladder cancer support group of which Wendy Sheridan was a member. I was thrilled when, several months later, she founded WebCafe and asked me to contribute this 'Ask the Nurse' page.

My Mom was a healthy 57 year old woman when she was diagnosed with bladder cancer. She had no predisposing factors (no smoking or chemical/dye exposure) but she had had an "overactive bladder" for about 5 years. She handled

the frequent urination by ignoring it and dismissing its importance. (To be fair, she had a lot on her mind. During this time, she went through a bitter, messy divorce and grave financial difficulties. She had to expend all of her energies on making a new life for herself. There was no time to be sick.)

Then in the fall of 1999, she began dating a former classmate. He had been in love with her since grade school; she couldn't really remember who he was. They fell in love and Mom decided it was time to take care of this little bladder problem. On December 22, 1999 she had a cystoscopy that showed a large carcinoma in situ. That's when I found out about the whole bladder problem.

I'm a critical care agency nurse. My job takes me to many of the hospitals in the Philadelphia/South Jersey area that need supplemental staff (and nearly all of them need experienced critical care nurses.) In the 5 years that I've been a nurse, I have worked at over a dozen hospitals, on more than 3 dozen critical care units. I love my job.

Critical care nursing, however, is not oncology nursing and I had never even seen a case of bladder cancer prior to my Mom's diagnosis. I felt ill prepared to advise my Mom but since I'm the only health care professional in the family, I knew I had to learn about it fast. I think that my most important contribution to my Mom's situation was steering her away from the community hospital that diagnosed her and towards a large comprehensive cancer center (the Hospital of the University of Pennsylvania) for her treatment.

On February 12, 1999 my Mom had a radical cystectomy with diversion to an ileal loop. She had requested that the surgeon perform a continent reservoir (Indiana pouch) but he did not because he found extensive metastatic cancer during the operation. Her pathology was T3aN2M1 (T3a = muscle invasive transitional cell cancer tumor; N2 = metastasis in multiple lymph nodes; M1 = distant metastasis to the ovaries and fallopian tubes.) This diagnosis of stage 4 was way worse than we expected.

She healed from the surgery well. About 3 weeks after the operation, she developed a lymphocele in the operative site that required a second hospitalization. Several weeks after this, she began a rigorous course of chemotherapy (M-VAC.)

The M-VAC lasted for the whole summer of 1999. My Mom was a terrific chemo patient. She had a great outlook and she took very good care of herself. I am proud of the fact that she did not get one single infection during this time.

Two weeks after the M-VAC course was completed, my Mom married that great guy in a Labor Day wedding (see pictures below.) In October, she went back to work full time. In November, she had a barrage of diagnostic tests and her oncologist and her surgeon declared her to be "in remission." She has gone about the business of reclaiming her former healthy lifestyle. I'm so proud of her.

If I can help you in any way deal with bladder cancer, please send an e-mail WebCafe. As I said above, I don't have any professional experience with bladder cancer. However, I may be able to translate medical jargon, explain procedures, or offer support in other ways. I'd be glad to help you if I can.

Sharon McMullen, RN, CCRN, BSN, BA

Urinary pH

Dear List,

Thank you for entrusting to me the job of finding out what an optimal urine pH value would be for a bladder cancer warrior. And here is my answer (drum roll, please): I don't know. Taa-daa! Pretty auspicious start to my cyberspace nursing career, don't you think?

Actually, I take comfort in the knowledge that the bladder cancer gurus don't know either. After careful consideration of the research, I have concluded that there is no clear recommendation as to which range of urine pH bladder cancer survivors should maintain.

So what's the next step? Simple. Ask your urology oncologist the next time you see him. It's very possible that he has strong feelings on the matter and will advise you accordingly. If he doesn't, make sure you tell him what you think and which plan of action you have chosen to make sure that it doesn't interfere with your treatment.

Your bladder cancer does not exist in a vacuum. Changing your diet significantly may pose problems elsewhere. Suppose you decided that a highly acidic diet would be a good thing for your bladder but you forgot all about that bleeding ulcer you had 15 years ago. Reactivated peptic ulcer disease would not be a good thing for a person battling cancer. Also, did you know that your urine pH will affect certain chemo regimens?

The bottom line is this: ask your doctor to prescribe what is appropriate for you. Making drastic diet changes without medical advice can be downright dangerous. Since the research is inconclusive, the most prudent course would be to rely on your doctor's advice.

Sharon McMullen, RN

See also Urinary pH

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Ureteral strictures

Hello all-

Do any of you have any experience with having scar tissue in the ureters? Supposedly it is common after a radical cystectomy, with an ileal conduit ostomy? (So a doctor has told us) Has it ever led to renal failure? My Father had this and I am wondering how common it is among bladder cancer patients.

Heidi

Dear Heidi,

My Mom had a C & D (radical cystectomy with diversion to an ileal conduit) in February. We were told that ureteral strictures (occlusions in the tubes that drain urine from the kidneys to the urostomy caused by scar tissue) were an expected, albeit unfortunate, outcome of this major manipulation of the ureters. Our urologic oncology surgeon cited an ongoing study of people who required urologic surgery at birth. A trend to develop ureteral strictures within 20 years was noted. So he told Mom to anticipate the need for ureteral stents and subsequent surgery to correct the problem within the next 20 years.

This is an excellent example of why you should maintain a follow up relationship with your surgeon. He will monitor your kidney function through blood tests (called BUN and creatinine), patient history (the part where you tell him if you've noticed any changes in your urinary habits), patient physical (where he examines you), and diagnostic procedures (like the IVP and renal ultrasounds) to determine if the kidneys are okay. Kidneys are resilient little buggers. They can take small hits (like periodic distension caused by short term blockages) and still come back to function properly. They are not nearly as fickle as the heart, for example, which will hold a grudge if you deprive it of oxygen for no more than 3 or 4 minutes. On the whole, if you keep up with the prescribed program, you should be able to avoid permanent kidney damage caused by a C & D.

I hope this answers your question.

Sharon

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Low blood counts

Dear Sharon,

My father was to have had a radical cystectomy (bladder, prostate and urethra) and urinary diversion on Aug.17th. The doctors did not remove the bladder or other organs because they discovered his tumour was extended into the pelvic bone and there was spread to the lymph nodes. We just learned 2 days ago that my father had a blood transfusion before or during the surgery due to a low blood count. I know a low blood count is very serious when doing chemotherapy but I'm not sure why.

Helen

Dear Helen,

I'm sorry to hear of your Dad's predicament. He's lucky to have you to help him through this ordeal.

You're right when you say that a "low blood count" is a serious problem for folks undergoing chemo. Blood is made up of several parts (including red blood cells, white blood cells, platelets, etc.) A complete blood count (CBC) is a blood test that measures these components. The 2 components that are prominent in your Dad's case are red blood cells (RBCs) and white blood cells (WBCs).

RBCs carry oxygen to the body. A significant amount of blood can be lost during abdominal surgery. If it is not replaced, the body will be starved of oxygen. This can cause stroke, heart attack, kidney disease, etc. That's why people undergoing surgery may require blood transfusions. RBCs are measured in hemoglobin (normal for men: 13-18, for women: 12-15) and hematocrit (men: 39-49%; women: 35-45%). (Please don't let me overload you with data. There is absolutely no need for you to know these particular numbers, it's just FYI.)

WBCs fight off infection. Chemotherapy can destroy WBCs to the point of leaving the body dangerously open to infection. Normal WBC lab values are 4.5-10. A value greater than 10 can indicate that you have an infection. A value less than 4.5 can indicate that you are at great risk for acquiring an infection. This data will be important to you when your Dad starts chemo because his WBCs will be tested before each treatment. If they are too few, the treatment will be postponed. Medication (like Neupogen) can be given to increase WBCs.

Please extend my best wishes to your Dad and let me know how things progress.

Sharon

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Neuropathy

Dear Nurse,

Last year, I had a 7 hour surgery to remove my bladder for TCC. Ever since then, I've had intermittent tingling and pain in my calves. My doctor says that I have neuropathy from being on the operating table so long. What can I do about it?

Thanks,

N

Dear N,

I'm so sorry to hear that you've had this discomfort for a year!

"Neuropathy" is a catch-all phrase for problems pertaining to the nervous system. Some examples of neuropathies include carpal tunnel syndrome (damage to the hands caused by repetitive motion), diabetic retinopathy (damage to the eyes caused by diabetes), and paresthesia (the "pins and needles" sensation that occurs when you cross your legs for a long time and your foot "falls asleep"). Some neuropathies are permanent but some are temporary. Often, the longer that blood is cut off from an area, the more permanent the damage to the nerves in that area can be. Also, some nerves are more likely to regenerate than others. In addition, some people are at greater risk for suffering nerve damage (diabetics, people with peripheral vascular disease, people with poor immune systems) than others.

The Association of Operating Room Nurses recognizes that patients undergoing surgery are at risk for developing nerve damage if they are not positioned appropriately on the OR table. There is a new "position paper" (giving recommendations to AORN members) on this subject (www.aorn.org/proposed/positions.htm) but the paper deals with prevention, not treatment.

So what can you do to relieve this type of neuropathy? Exercise, massage, hydrotherapy (whirlpool, etc), TENS (electrical stimulation of affected nerves), good diet, and smoking cessation are a few recommendations that some AORN experts have mentioned that may decrease the pain associated with neuropathy. Of course, not all of these recommendations apply to everyone. Massage, for example, can be inappropriate for some people with cancer. Check with your doctor before you start any new course of therapy.

I hope you will talk with your doctor on how you can get relief from this condition.

Sharon

note: see also surgical pain

Dear Sharon,

I don't understand my male companion's attitude towards his bladder cancer. I think he should have whatever surgery will give him the best chance at surviving. He says that, as a woman, I don't understand how he feels. Also, he doesn't seem to want to talk about his diagnosis with me. Is this common?

Signed, H

Dear H,

I'm so sorry about your Companion's bladder cancer. It's a rotten thing to happen to a nice guy.

From my experience on WebCafe's e-mail support group, I can tell you that men seem to handle this diagnosis differently than women. Most of the women seem to want to get rid of the cancer, regardless of the cost. Most of the men, on the other hand, seem far more worried about implications (urinary diversion, change in sexual function, etc.) of this surgery. In fact, a few months ago, a group of men on our List were commiserating about the loss of sexual function that a prostate removal can cause. A couple of the women said, "Hey, you don't have much of a choice. Either get it out or face a very grim prognosis." So one of the men wrote back that women wouldn't really understand. We had to gently remind these guys that women who undergo radical cystectomy also get a total hysterectomy and vaginal wall revision to boot. Men and women just seem to have fundamental differences in the way they view this surgery.

Many of the men in our group have expressed great relief at being able to "talk" about this disease with other men who have the same diagnosis. And sometimes it's easier to bare your soul to a stranger online than it is to "burden" your loved ones with your problems. Is there any way that your Companion could check out WebCafe? It offers a wealth of information that anyone facing cystectomy should have. If he's computer shy, maybe you could print out a few pertinent sections and leave them on top of his morning paper. I'd suggest including Tales from the Trenches so that he could read the stories of folks in his situation.

However, you might not be able to get him on board. My Mom avoids bladder cancer information/discussion like the plague. Once she made her decision to go ahead with the surgery and then the chemo, she didn't want to think too much about it. But she always said that she appreciated that I kept abreast of the subject. She felt comfortable delegating the responsibility to really know what was going on to me. Then if she had any questions she could ask me in her own time. Also, when she was in the hospital, she did not want to deal with the doctors so she just waved their questions toward me. It was a little frustrating to me at the time, but now I can see that she needed to not "become" bladder cancer. It was her way of keeping her distance from the disease.

I'm sorry that you're faced with this situation. Please keep in mind that you (as a caregiver to a bladder cancer warrior) are welcome to join our support group as well. Good luck. I hope you'll let me know how things work out for you.

Sharon McMullen, RN, BSN, CCRN

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Chemo and the Kidney (3/26/2000)

Sharon, or anybody who knows about this. My BUN and creatin #s are not good enough for MVAC Chemo treatment. The new Dr. thought there might be a way around to better these numbers by collecting 24 hours my urine and then have it tested for these numbers in a LAB (will be done day after tomorrow). I wonder if this would be accurate or maybe harmful by getting the chemo anyway.

Hildegard

Dear Hildegard,

BUN and creatinine are routine blood tests that measure kidney function. The normal values are 8-20 mg/dL for Blood Urea Nitrogen and 0.6-1.2 mg/dL for creatinine. Higher values generally reflect inadequate waste removal by the kidneys. I'm not sure what your doc will find with a 24 hour urine collection that the BUN and creat haven't already told him. I'll be interested to hear.

Many chemo meds are especially nephrotoxic (poisonous to kidneys) including MVAC. If a person has poor kidney function to begin with, MVAC could possibly damage the kidney permanently.

Kidneys filter waste from the body. If a person doesn't have good enough kidney function, the body becomes poisoned by the unfiltered waste. Luckily, we do have a treatment for this: dialysis. Unluckily, it's a rotten treatment. Don't get me wrong, lots of people live long and productive lives on dialysis, but it's not an easy road. If anyone would like more info on the different types of dialysis, let me know.

The larger issue, of course, is prioritization. What's more important to you: a chance of getting rid of the cancer or keeping your remaining kidney healthy? What good is a healthy kidney to a person who is being killed by cancer? On the other hand what's the quality of life for a dialysis, but cancer-free, patient? Or are there other less nephrotoxic chemos that would give just as good a chance of killing the TCC as MVAC would without damaging your kidney. Tough questions. Good thing you're a tough lady.

Sharon

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Pathology Report? (1/2/2000)

Dear Sharon,

Dad just had his post-op follow-up, after cystectomy on Dec 1. We found out that his prostate was cancer-ridden as well, which he never bothered to tell us. But after being fairly certain that the cancer had been contained in the bladder (per post-surgery discussion), the doctor said that the pathology report showed it had escaped out of the bladder into the fatty tissue in a very small spot. So he'll have cat scan in 2 months, and wait re: chemo decision until then.

My question is can't they see that it escaped the bladder while doing the surgery? And how does pathologist pinpoint that it poked thru in only a "small" area? I realize that it doesn't take much of an escape to cause problems later on, so I'm not being misled by the description of the size. I'm just wondering if anyone knows the procedures used to determine this. Thx! And may everyone have a happy and HEALTHY New Year!!

Gerri

Dear Gerri,

I'm sorry to hear that your Dad's pathology was not absolutely clear. You wrote: "can't they see that it escaped the bladder while doing the surgery?" If the infiltration is large, then yes they can see it during surgery. But cancer starts out at such a small, microscopic level that a surgeon wouldn't dare trust his own eyes to rule out spread. That's the beauty of pathology. The pathologist will examine the tissue through a microscope to look beyond what the naked eye can see.

You wrote: "And how does pathologist pinpoint that it poked thru in only a "small" area?" Because he thoroughly examines the whole bladder. That's his job. There's a pathologist online at pwww.pathguy.com. Read his site (with a large grain of salt, he appears to be a bit of a character) for a better understanding of the very cool science and art of pathology.

Sharon

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Time Delays (12/14/99)

Dear Ms. McMullen,

My grandmother, who turned 69 last week, was diagnosed with bladder cancer about 3 weeks ago... Should we be concerned with the amount of time that has passed (and may continue to pass) since her diagnosis? Time is ticking by...I don't know what to do. ... Am I over reacting?... Please help!!

Thank You for your time,

Regina

Dear Regina,

I'm so sorry to hear about your Grandmother's illness. You're right, this is an urgent matter in that it needs to be addressed in a timely fashion. It is not, however, an emergent situation (like a heart attack or stroke is). Remember this type of cancer does not appear overnight. It grows for years before it gets to this stage.

The delays are frustrating to you but don't panic. Even if she opts for surgery, it takes a few weeks to do all the necessary pre-op tests and to schedule the surgeon. Use this time to learn as much as possible about bladder cancer. I have noticed that sometimes the patient prefers to assign to a family member or friend the job of learning the "technical stuff." My Mom didn't have a real drive to know the specifics but she always said that she felt better knowing that I knew them. Then she could ask me things when she was ready to hear the answers. Maybe you could do this for your Grandmother.

Sharon

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[Problems with the Hospital \(12/28/99\)](#)

Dear Sharon,

I had a bad experience with unresolved pain after my surgery at (a well respected hospital) in Philadelphia. What can I do about it now?

Signed, S

Dear S,

I'm sorry about your episode with unrelieved pain. Please, please, please send that info in your own words (as you have written in another post) to the president of the Hospital and also cc: it to the Nurse Manager of that floor (you don't need her name, just address it to "Nurse Manager, Silverstein 11 (or whichever floor it was) at the hospital. These are the people who make the unconscionable decisions to cut nursing (and pharmacy, and lab, etc) hours to the point where the patients are in danger. "Gee, in the red again this year? Well, let's just fire 134 more nurses. That'll save us a bundle! And the patients don't seem to mind, because they hardly ever complain..." I worked at that hospital from 1994-1995. It was a great learning experience. I can say without a doubt, after having worked in over a dozen hospitals in this area, that it is finest hospital in Philadelphia. The problem that you so eloquently describe is a failure of the hospital's policies and procedures that could be fixed if more money was spent on more nurses (and pharmacists, and lab techs, etc). My Mom suffered several complications that resulted from miscommunication within the hospital. It was tiresome to correct them all, but we did. These problems didn't occur because we had "bad" nurses/docs/etc, but because so many hospital policies are created by people who haven't seen patients in too many years. Let these policy makers know what happened to you and maybe it'll make a difference. Your story also illustrates the reason why I wouldn't think of allowing my family member to be unattended in any hospital at any time. We stayed with my Mom 24/7 to head off this type of thing. How crazy is this world when you can't trust that you will be safe from unnecessary suffering, even in the best of hospitals.

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NG Tube (2/4/2000)

Sharon, it would be great if you could explain that blasted NG tube, I call it a nose hose, what is it for, why we need it. Here's something I did because of that darn tube...my throat and nose were so dry I would have the nurse give me a hot wash cloth and I'd put it over my face and breath through it like a facial mister, it was great and really gave me relief from the dryness in my nose and throat...actually, it was almost as good as the nose spray.

Kathy

Dear Kathy,

"Nose hose", heh-heh, that's a good one. The NG tube is a rigid plastic tube with a couple of holes near the bottom. It is inserted into one nare of your nose (naso = nose) and goes down your esophagus into your stomach (gastric = stomach). The naso-gastric tube is a wonderful thing because it removes the gastric acids from your belly before they can go down into your intestinal tract and make trouble. It can be set to suction (to actively remove the gastric acids) or it can simply be capped (but be available to go back to suction if problems arise.) I have inserted many, many of them. Most people are amazed that something that thick (about the diameter of a small magic marker) will actually fit into their nose.

So why is it necessary? Here's the thing, your stomach wakes up after surgery much more quickly than your colon does.

The stomach secretes gastric acids. The acids drain into the colon. If the colon is still under the influence of anesthesia, the gastric acids will get stuck and could cause a blocked bowel which could then perforate (a very bad, potentially life threatening situation.)

Sharon top