

## Trench Talk - about non-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 concerning non-muscle-invasive bladder cancer.

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What can I expect from BCG?

I have written the list several times asking questions during the period when my uro was conducting tests to determine whether I had bladder cancer or not, and to what degree. I greatly appreciate the helpful responses I got from many people. They helped me immensely through the pre-diagnosis stage.

I have now had biopsies, cystoscope exam and retrograde pyelogram test under anesthesia, and a final diagnosis of high-grade, non-invasive superficial bladder cancer has been made (CIS). A 3-4 cm area close to the left ureter is involved, with some involvement of the lower part of the ureter. A stent was installed to avoid closing it off during the resection and cauterizing of the affected area. The area is described as a rash-like pimply area, with the largest nodule 1/2 cm in size, and no muscle invasion.

I am scheduled to undergo a series of BCG treatments - one a week for 6 weeks. I have been given and understand the mechanics of what will take place. However, I would like to hear some first-person accounts of what to expect afterwards. The instillations will be given in the uro's office, and then I will be sent home with instructions to withhold urination for 2 hours. I have been given the precautions on sterilizing the bowl, etc. What I would like to know is:

- How fit will I be to drive myself home? Is it better to have someone

come with me to drive me home so I can recline in the passenger seat and relax? I'm worried about being able to hold it

for 2 hours in 25 miles of heavy city traffic while driving.

- The printed instructions talk about laying first in one position,

then another, to make sure the solution contacts every portion of the bladder wall. How practical is this if one is sitting up in a car on the way home? Also, how will the solution contact the upper portion of the bladder where the cancer is, considering the effects of gravity? The uro's nurse says they don't have the facilities for me to stay in the office until I have voided.

There is also a sanitary problem there in using the restroom which so many other people use, as the solution is basically a tuberculosis bacteria vaccine solution.

- How will the BCG solution coat the lower portion of the ureter if it has a stent in it? The uro said the stent had tiny holes in it, and this, along with capillary action along the sides, would suffice. Is this correct in others' experience?

- What are the usual after-effects? Can one resume normal activities after voiding, or is a period of rest advisable?

I plan to do the test and go home for the rest of each day. Will I be able to resume work the following day? In summary, what should I expect from this experience in terms of discomfort, mobility, ability to work, etc. I should have asked more of these questions during my consultation, but I was so stunned by the confirmation of cancer that I failed to do so at the time. Also, I've already discovered that doctors and nurses tend to understate the after effects of procedures, in my experience.

Thanks to anyone who has first-hand experience with BCG treatments of this type and is willing to share the details with me. I am so grateful that this list exists, as I would feel very alone without it. I know no one else with this condition, and other than the printed word and my busy uro, have no where else to turn for help with questions.

Many thanks,

Paul

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Hi Paul--No one can tell you exactly what to expect because each person's response can be different. Many people have a very easy time of it and others struggle with some symptoms

> - How fit will I be to drive myself home? <

I'd be concerned about that myself--you'll probably be distracted by the very fact that the BCG is sloshing around and that's not a good mind set for driving. Bring a friend to drive if you can.

> The printed instructions talk about laying first in one position, then another, to make sure the solution contacts every portion of the bladder wall. How practical is this if one is sitting up in a car on the way home?<

You could recline the seat as much as possible and shift around somewhat--Some people don't turn at all and have good results.

> Also, how will the solution contact the upper portion of the bladder where the cancer is, considering the effects of gravity?<

The bladder will fill up gradually anyway during the time span of two hours and the solution will reach everywhere--no one has actually stood on their heads to get it to the top as far as I know!

> How will the BCG solution coat the lower portion of the ureter if it has a stent in it? The uro said the stent had tiny holes in it, and this, along with capillary action along the sides, would suffice. Is this correct in others' experience?<

I don't really know but it sounds very plausible to me.

> - What are the usual after-effects? Can one resume normal activities after voiding, or is a period of rest advisable?<

You'll have to see how you feel--some people get very tired and others are just fine--play it by ear.

> I plan to do the test and go home for the rest of each day. Will I be able to resume work the following day?<

Probably. I'm sure you'll hear from others about this. You'll have to take it one treatment at a time and no one can truly forecast what it will or won't do. Good luck with it.....Barbara

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Paul,

I was in a 2-year study program of treatment with BCG + Interferon-alpha, after being unsuccessfully treated by scraping (TUR), fulgeration (cauterization), and BCG alone April through December of 1999. I had CIS, similar to yours, but no stent. I had negative biopsies after the first 6 week series of treatments with the latter, and for nearly 2 years since then (the 2-year study program just ended). I was fortunate enough to be able to stay in the treatment room for 2 hours, until the last series of treatments I had, when I had to go home, an hour to hour and a half of combined walking, subway, & suburban city traffic (Washington DC to Maryland suburb).

>How fit will I be to drive myself home? for 2 hours in 25 miles of heavy city traffic while driving.<

I sometimes had difficulty making it 2 hours without going to the bathroom after the treatment. It wasn't usually a problem, and I think it was a matter of how much I recently had had to drink. It also helped to lie still in bed.

>Also, how will the solution contact the upper portion of the bladder where the cancer is, considering the effects of gravity?<

I think it will compromise the treatment. If your cancer is diffuse like mine, there could be cells in the upper area that you want to have affected. It'll probably slosh around some while you're moving, and maybe that'll be enough, but there's a reason for those instructions.

>I plan to do the test and go home for the rest of each day. Will I be able to resume work the following day?<

AND DRINK LOTS OF WATER. Pour yourself a pitcher of 4 - 6 cups and drink at least that within the next couple hours after the 2 hours. Continue drinking lots of water. You will most likely be fine the next day.

> The printed instructions talk about laying first in one position,

then another, to make sure the solution contacts every portion of the bladder wall. How practical is this if one is sitting up in a car on the way home?<

If you can't lie down and roll around, you're decreasing the distribution of the medicine. It's certainly not practical at all sitting up in a car going home.

>I was unhappy being told for the last treatments I couldn't stay. I stopped at a nearer point (after an hour travel by foot and subway) at my father-in-law's, where I could lie down a greater part of the 2 hours than if I drove home from the subway.<

I recommend against it. a) find a place close by where you can lie down & roll for 2 hours, or b) have another driver & do the best you can but I hesitate to say do anything that would take you out of the seat belt. c) If you're really stuck, I'd err on the side of being fanatical and pull over every 15 mins or so if you can, & recline & rotate. You might bring something to urinate in if you could to be in a position where you can't get to a rest area. You might not have any problem at all.

You want to do everything you can to help the treatments work. This is serious business. Getting home in 2 hours or going to work the next day is relatively unimportant.

>What are the usual after-effects? Can one resume normal activities

after voiding, or is a period of rest advisable?<

You will be able to resume normal activities. Keep drinking water. Go with how you feel. I had pretty strong discomfort and urgency to urinate as a result of irritation from the treatment. Usually no fever, but I eventually had a mild fever after a few treatments, but not immediately after the treatment. I also experienced a burning sensation urinating & some pain afterward. I didn't always experience much if any of that. The burning sensation seemed to correlate with not being careful to follow the advice to drink lots of water afterward. This is going to produce an immune response within the bladder. At least in my case, this produced an irritation of the bladder that lasted long after the treatment and until the next 3-month cystoscopy. This inflammation

is indistinguishable from cancer cells, so I had biopsies every 3 months. Only this last time, this month, May 2002, after 3 years of treatments, was the inflammation reduced so much that there was just a small area of it. The urologist took only one biopsy this time. I don't have the results yet. I'd had my last BCG+Inton A in 12/21/01.

The BCG also irritates the prostate gland. I don't have a full understanding of that, but it results in nodules & affects the digital exam. I thought I was told it could affect the PSA (until the response declined, and it persists long after the 6 weeks if you respond), but when I asked that question to confirm it, I thought I got a different answer. Anyway, I have a measurements of my PSA that showed it had increased, after being treated with BCG, and has come down.

I don't have a lot of measurements, and from what I have you couldn't say if it was due to the BCG with certainty without

more information or knowledge.

>Will I be able to resume work the following day?<

You should be fine. I had irritation and urgency to urinate. I may have more details recorded about that & you can ask me about that.

Maybe you can rent a room nearby. If you do, it will probably be overkill & you'll question yourself (or me) about doing it, but it would be good to be able to relax immediately after the treatment where you can see for yourself how you react. 2 hours in heavy city traffic with an irritant in your bladder could get uncomfortable.

Oh yes - after the 1st treatments (6 weeks), with BCG alone, I could drive home, because the urologist's office was nearby. By the next treatments, I was seeing a different urologist.

Now I'm going to want to hear how you do.

Sanford

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Paul:

Strongly suggest you check out experiences of some of us at WebCafe. I feel that your visit to that site would answer most of your questions. Also strongly advise that you have a driver. Good luck. I was similar diagnosed and also had a stent for a year. Feel the 12

BCG treatments (6 weekly and 6 monthly) helped greatly. I have been clear for 2 1/2 years.

Yours in Christ

Paul Morton

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Hi Paul,

I went through the same procedures Feb/March this year. I too, after what seemed endless trips to the clinic and several poke & peeks was dx with CIS. They removed what they called the 'larger Tumors', then gave me 4 weeks time off for things to heal and get back to normal after which I started my first set of six B.C.G. treatments which were done at the London Regional Health Science Center. For this I drove myself (approx. 30 minute trip) to and from. First time I had my

wife come with me since I didn't know what to expect. The actual treatment was done by nurses of the Urology Department and I must say was no way as uncomfortable as when my Uro went in for a poke & peak. Going home was no problem since reactions (if any) only appeared after a couple of hours or so. Also as a emergency standby the nurse had given me a plastic jug and so if needed I had an option.

Regarding the laying down and turning over at 15 minutes intervals they had decided her that there was enough agitation within the bladder that it wasn't relay necessary. More important was drinking 8 glasses of water a day to get rid of the BCG. First night wasn't too good. Many trips to the bathroom and somewhat sore. But then on day two all was well and I felt better that I had for many months. Yes I had to visit the bathroom frequently but always with positive results and less pain. After my six weekly treatment I still felt good for another two weeks. But then the proverbial hit the fan. Again I experienced the urgency to pee but found it difficult and painful and sometimes dried up all together. I contacted my Uro's office was given a prescription for antibiotics and had to wait for my next scheduled Cystoscope. When it came I was a mess and after having a quick peek the Uro told me that I was the one in ten patient that had an adverse reaction to BCG and scheduled me for another Biopsy since apparently every thing in my bladder is on the war path. For this I must wait until May 28. Not quite sure how. It hurts like hell!!

Sure hope you are not one of us unfortunates and I wish you all the best.

Horst

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Paul:

I don't recall being told to lie in different positions while have the BCG in me, though I might not remember being told.

After my BCG treatment (post void), I had a great urgency to pee. Most times little or nothing would come out. By the 6th treatment, I was very close to

have some urinary leakage.

The night of the treatment, I stayed home. For the next two days, I tried to stay as close to a bathroom as possible, as I sometimes had to pee every 15 minutes or less.

I also had tissue discharge during some urinations as well as some blood. It was never painful, except some spasms during urination and they were only

uncomfortable.

Good luck and best wishes on a successful treatment.

Ron

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Paul, it is certainly understandable that you can't remember to ask questions

after your diagnosis - I have had 3 separate 6 week instillations of bcg over the last few years - can't answer your question regarding the stent - as far as the changing positions for 15 minutes, I think if possible you should ask if there is another facility closer to home where you could have the instillations done or a room where you can do this turning as it is probably important - I always had a mild burning and urgency following the first few treatments but nothing more serious (and it wasn't a problem holding it for the 2 hours) - I would want a washroom close for the first 3-4 hours - as you get to your 4th, 5th and 6th treatment this gets worse and lasts longer but in my case still wasn't too bad and I was able to go to work the next day.

Good luck,

Regards,

Jim

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Welcome to the BCG adventure! It's difficult to say for sure exactly what you will experience because it can vary a lot. Some people have very strong reactions, become very ill, and need treatment for the side effects. In my case, the side effects were minimal and didn't interfere at all with my well-being or activity level.

First of all, don't eat or drink anything for four hours before you get your instillation--longer if you can. This will help prolong the time you can hold the BCG. Some uros recommend holding it for more than 2 hours if possible. I've been able to hold it for up to 4 hours.

Your drive home should be fine. That will coat the bottom of your bladder. Then, when you get home, lie down and begin your rotisserie action. Fifteen minutes on a side, then turn. Don't worry about the dome of your bladder--no need to spend 15 minutes standing on your head. It'll get coated just fine in the other positions. In fact, some uros say that because the bladder, like a balloon, shrinks to accommodate what's in it, you don't need to get into any special positions at all. The bladder will simply have contracted to the volume of the instillation and everything will be coated.

I usually took the whole day off for my instillations, and scheduled them for Friday so that if I felt badly the next day I wouldn't have to worry about work. However, I never felt badly the next day, so it wouldn't have mattered.

As for coating the ureters, I don't believe that the BCG generally gets up there much unless they are specifically dilated. The stent might actually help the solution reach that area.



Be sure and read the entire Lamm protocol on the Bladder Cafe site so you can be prepared if the side effects do turn out to be severe. Most uros don't have the experience to know what to do, so you need to be informed just in case. Remember--if the side effects are still present when it's time for the next instillation, postpone it. No harm in doing that, and much potential harm in not. If you are very sensitive, and respond severely, ask the uro to reduce the next dose to 1/3, 1/10 or even 1/100. As long as you are responding, your body is doing what it needs to be doing.

However it turns out, best of luck!

CB

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Hi Paul,

I agree with the advice given herein. I would ad two thoughts. In my case (had BCG treatment yesterday) Go for the BCG as early in the morning as you can and don't drink any liquids from midnight on. If you need to take medicine use the least amount of water possible or if possible postpone the medicine until after the two hour wait. After the two hour waiting period, drink two 8 oz glasses of water and then 8oz water every hour (I do 8oz every 1/2 hour) I repeat - It works best for me to not drink any liquids or eat anything from midnight on. Then drink lots of water after the two hour wait period. The idea is to flush out the bladder so the more water the better up to 8oz every 1/2 hour to hour.

The only time I had trouble holding the BCG for two hours was when I drank some water the morning of the treatment.

Ed in California - You and All BC Cafe Warriors are in my Prayers.

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Good morning Paul,

RE: your BCG questions

I have had six BCG and nine BCG+Interferon A instillations. BCG is meant to stimulate your immune system by irritating your bladder. It does this very well.

We all suffer different levels of discomfort or side effects from BCG instillation. Hopefully, yours will be minor one. The effects range from hardly noticeable to the point where treatment has to be discontinued after just a few instillations. Someone on this list did a survey of BCG symptoms and posted the results several months ago. Perhaps she will email you a copy. Or you can search the archives for this list. You can also get basic info on side effects at <http://rxlist.com> or [www.nursesprdr.com](http://www.nursesprdr.com).

I suffer from minor irritation pain (first day only), urinary urgency, frequency and leakage (without warning I dribble a few drops to a couple of ounces) for three to four days. My solution is to take an incontinence diaper to the instillations and put it on immediately afterwards. I typically have to wear a diaper for three to four days after instillation day. I keep one in my attache case, a couple in the car, several at home and several in the office. Have tried the Depends and a couple of other brands and reached the conclusion that the best for urine containment and ease of use are those that are one-piece briefs (no need to attach with Velcro strip or button on two straps to create a diaper). I found the best

fit at Walgreens or Target. Incidentally, I'll be 64 the end of this month, prostate is okay, have had bladder cancer for over nine years and had no incontinence problems before I met BCG in October of 2000. (Had no prior BCG because of two totally incompetent urologists and their stupid patient who didn't know any better.)

I'm a self-employed business consultant/writer and usually return to the office later the same day and continue with my normal schedule thereafter. If you feel especially tired (BCG sometimes affects us that way), take a day off and rest.

You may also decide to carry a covered quart jar to use as an emergency urinal in your car, a large towel to put over your lap while you're filling the bottle, and some toilet or facial tissue and handiwipes for sanitation afterwards.

Regarding drinking water, DON'T for several hours before the instillation. Start again, as someone recommended today to drink several glasses in the first few hours AFTER the two-hour hold period. If you drink a lot before the instillation, your bladder will continually fill and dilute the BCG. The instillation consists of an amount about equivalent to a bottle of eye drops, approximately 40 ml. Your bladder capacity is approximately a half liter, 500 ml.

The literature from the Tice BCG supplier states: "TICE BCG is retained in the bladder for 2 hours and then voided. Patients should void while seated in order to avoid splashing of urine. For the six hours after treatment, urine voided should be disinfected for 15 minutes with an equal volume of household bleach before flushing. Patient should be instructed to increase fluid intake in order to 'flush' the bladder in the hours following BCG treatment. Patients may experience burning the first void after treatment."

For the text of the entire six pages printed material that is packaged with BCG, go to [www.organoninc.com/pi/tice\\_pi2.html](http://www.organoninc.com/pi/tice_pi2.html).

Have not had a stent and cannot advise on how BCG will reach the affected ureter. My understanding is that the stent is a tube used to keep the passage open and to promote healing of the ureter. I am not a medical specialist but I believe you need clarification from your doc on whether the stent has holes in it or otherwise how BCG can reach the ureter. You might want to search "stent" on medical websites or my favorite, [www.google.com](http://www.google.com). Use Advanced Search on google for multi-word search terms.

I agree with the people who say that you should find a comfortable place to rest, reposition yourself and void safely after the instillation. Take along your bleach and don't forget to sanitize your diaper if you use one. Otherwise you may need to bleach some of your clothing. Bleach is hell on dark slacks and blue jeans.

I believe it makes sense to change positions in order to ensure that the BCG provides equal irritation to all portions of your bladder. I've seen advice pro and con on that.

Hope this is helpful. BCG works wonders for many patients. Good luck with your instillations!

Roger in AZ, 63 and counting

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Everything I've read said 2 hours, if you can. Would like to see a reference

to other recommendations. Manufactory recommends rotation, Dr.Lamm in his older write-ups had people lay on their stomach for 15 minutes before he let them go, as instillation results in formation of air bubble, my Dr. said moving around was enough, my thinking was to coat the bladder by rotating, starting with the location of the tumor first under the assumption that the urine will dilute the BCG with time. Laying down and rotating allowed me to hold the BCG for the required 2 hours most of the time. Was able to complete 24 treatments before the BCG did me in with urination burning for a month. Remember too much BCG is not good either.

Click here: [Dr Lamms protocol](#)

Tom

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Paul I have taken at least 24 BCG treatments, and start more with interferon in 3 weeks and so far I have had very little side effects. I can always hold it for two hours although I do some dancing the last 15 minutes!

My wife used to go with me, but now I usually go by myself and have had no problems. I have been lucky...some have many bad side effects, ie headaches, nausea, burning etc. Apparently everyone is different. The first is usually easier than the 6th.

I used to lie down and turn over etc. but, the bladder is actually smaller than you realize and the solution slops around and covers everything (even riding in a car)

I do not agree with CB about keeping it in the bladder "long as possible." I was told to keep for 2 hours....longer may not be better! it is very potent stuff! (That is what I was told!)

Good luck! Jack

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I was told the longer the better.

K

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Guess these uros ought to talk with each other and perhaps have some kind of consensus on this subject.? I will pursue with mine in a 3 weeks, and will advise.

Jack

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#### 4th BCG instillation

I had my forth today at 11 AM and by one PM I was sick again, fever, chills, diarea, and bleeding when i urinated. still an hour from home, we made 4 more stops at restrooms for me to throw up and bought a bottle of bleach each time as we didnt want to leave any of this nasty stuff behind. I have a theory that might be of some conciquence; The VA hospital only has one size of catheter, size 14?, anyway i think there is collateral damage each time and it is getting into my bloodstream.

That's why i get sick so soon. I am going to try and buy some smaller caths before i go back and ask that they be used. Since i had no damage before installation it must be that my passages are too small or is damaging the prostate valve during insertion.all i really

know is its hurts like hell and it makes me sick. Fred

\*\*\*\*\*

Dear Fred,

Call the doctor, you shouldn't have fever, chills and bleeding. If there was trauma with the catheter and they actually caused damage and then proceeded with BCG, the clinic or whatever it is should be closed down as they don't know what they're doing.

Wendy

\*\*\*\*\*

definitely agree with Wendy. Check the PDR for BCG treatment, it provides a warning about trauma to the urinary system - don't use the BCG if there is trauma to the bladder!!! I had the same sad experience when I had my first six BCG treatments. The catheter insertion should not hurt, and if it does, then either the nurse or doctor is doing the procedure wrong. However, I should note that there can be some exceptions for patients with IC (interstitial cystitis). I have IC and so the nurse uses a local (inserted in the urethra) and waits for at least ten to fifteen minutes for the local to fully take effect. If you have IC, your urethra is pretty much inflamed and so much care needs to be taken for this situation. I know that there has been various postings as to whether a local will diminish the effectiveness of BCG. I have seen information that says the local will affect the BCG and some information that says there is no known effect on the BCG. But, in my case, this is a moot point because without the local, I could not have continued the BCG treatments. Best wishes, Sam.

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Fred,

From what my medical attendants say, it's ok to have fever, chills and even bleeding if they clear up in a day or two. The following is from Organon's Website (Tice BCG): <http://www.organoninc.com/products/index.html>

"Management of Serious BCG Complications."

Acute, localized irritative toxicities of TICE® BCG may be accompanied by systemic manifestations, consistent with a "flu-like" syndrome. Systemic adverse effects of 1-2 days' duration such as malaise, fever, and chills often reflect hypersensitivity reactions. However, symptoms such as fever of 38.5°C (101.3°F), or acute localized inflammation such as epididymitis, prostatitis, or orchitis persisting longer than 2-3 days suggest active infection, and evaluation for serious infectious complication should be considered.

In patients who develop persistent fever or experience an acute febrile illness consistent with BCG infection, two or more antimycobacterial agents should be administered while diagnostic evaluation, including cultures, is conducted. BCG treatment should be discontinued. Negative cultures do not necessarily rule out infection. Physicians using this product should be familiar with the literature on prevention, diagnosis, and treatment of BCG-related complications and, when appropriate, should consult an infectious disease specialist or other physician with experience in the diagnosis and treatment of mycobacterial infections.

TICE® BCG is sensitive to the most commonly used antituberculous agents



(isoniazid, rifampin and ethambutol). TICE® BCG is not sensitive to pyrazinamide."

I haven't had a problem holding it two hours, but after I start voiding it, I do have diarrhea sometimes, but I haven't had to throw up. Make sure that you are not dehydrated prior to treatment. Drink plenty of water the day before treatment, but nothing within 4 hours. Two hours after the treatment start drinking a lot of water again. I've had fever and chills but no visible bleeding. The chills did not start during the initial six treatments, but started during the first maintenance BCG treatment of three (2nd of the 3). My fevers have always been less than 101 deg F. Fever and chills have started about 6-10 hours after the treatment. The fever will break about 12 - 18 hours after treatment and the chills will stop. I will continue to feel bad the following day, and will start to feel better about 24 to 36 hours after treatment.

I think I had a traumatic catheterization during #4 of the first 6 BCG treatments. The follow-up biopsies after my TURBT showed granulomatous infection of the prostate. I think I also had an infection of my liver from the BCG, indicated by elevated liver enzyme levels. According to the literature, some of these infections can resolve themselves without treatment.

I asked them to use a smaller catheter, a number 12. I think they may call it a pediatric catheter. It goes in a lot easier, but they have problems with it folding over (not as rigid).

Your reactions seem to be pretty severe. You need to talk to your doctor about your reactions.

Regards,

Barry

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By all means, yes, drink lots of water after the 2 hours. I found it eased discomfort to flush it out then as rapidly as possible. By lots, for me that meant I'd set out maybe 1 1/2 liters, 6 or more cups, & drink it before the day is over, instillation having occurred by mid-day. Otherwise I'd be more likely

to experience burning. I had BCG + Interferon-A every 3 mo. for > 2 years.  
Encountered little problem with catheters except one nurse/technician had a lapse in how to administer the treatment & put me through some extra discomfort. Elevated temp didn't usually occur & was not of great significance.

Sanford

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#### Discomfort after 7 weeks/TUR

Hello, BC fighters: I have a question. I'm 44 year-old male non-smoker dx with BC 11/2000. I had TURBT seven weeks ago to remove two Ta Grade 3 tumors, one was 3 cm and one was 5 x 8 cm. Also found CIS. Since the surgery I've had a number of medications (Pyridium, Hyoscyamine, Ciprofloxacin, various pain relievers) but I'm off them all now. I continue to have urgency to pee and low level pain in the bladder and urethra until I empty the bladder. This has been unchanged for a month. My urologist tells me it's due to the large raw areas that resulted from the tumor removal, and says I may feel this way for 'a couple months'. I start eight weeks of BCG this Friday. Is it "normal" to have post-surgery effects for this long? Thanks for all the great info & support, J.C.

\*\*\*\*\*

I am afraid to say that what you are experiencing sounds quite normal, if my experience is any indication. I've been through three TUR's and a whole bunch of BCG over the last two years, and at this juncture I'd have to say I always know my bladder is there. During the few months after surgery there were times when it was just a slight irritation and some times I needed to take a couple of Tylenol to relieve the pain enough to enable sleep.

My doc used the comparison of biting your gum or the inside of your mouth. He said the bladder is comparable, in that it's always wet and takes time to heal. He also said that when they do these TUR's they cut well into the muscle so that they can stage and grade the tumor. Your tumor sounds like it was pretty good sized. 3 cm is 1 1/4 inch. 5 x 8 would be 2

x 3 inches. That's plenty of healing. Dave

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> Is it "normal" to have post-surgery effects for this long? >

Given the size of your tumor, probably normal. Tom

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Dear J.C. The largest of my tumors was 4-5 cm and my experience was much different from yours. After leaving the hospital at 9:00 p.m. and having a good rest, I was up and in the garden the following morning. Once the catheter was removed (the third day after the surgery), I felt terrific. I still do! I have never felt an urgency or pain since my tumors were removed and they too were in the trigone area. I had to use only one of the pain pills after the surgery. So in response to your question, your experience is different from mine. Best of luck. LaNette

\*\*\*\*\*

Hi, When my urologist prescribed BCG after my second TURBT, the nurse scheduled it for four weeks after the surgery. I was not in agreement with this, since I was supposed to take it easy for six weeks and so as not to damage the affected area, yet they were ready to put BCG in there before that. I changed the appointment to six weeks after the surgery for my own peace of mind. Connie

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J.C., I don't think there is any one answer as to how long the "sensitivity" will last but as a vet of 4 turbt's and one set of BCG in a year, I can tell you that things change and probably won't ever be the same. I have the same urgency to pee - when you gotta go, you gotta go!. Also burning after surgery different sensations in the GU area. I think it goes with the territory. Ralph

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As easy as I get thru TURBs, without bleeding and or caths, etc....I still have sharp shooter pains occassionally for a few months after....cystitis feelings begin as well off and on and its usually when I forget to drink enough water, but the old baking soda and water cure usually clears it up, just as when the spasms start.... I think as there is no one treatment to handle all bladder cancer, there is also no one clear path of healing time for each individual..... Pat

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Hi, Don't know if this will help much but, my husband experienced the same thing after his TURBT in November. He is also concerned, but according to the doctor it's normal and everyone has their own rate of recovery. Carol

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## Pain and Incontinence After BCG

Hello All,

I had TCC, and a massive, non-invasive tumor was removed on November 16th (2000).

I finished BCG treatments five or six weeks ago, and I am wondering what you people feel about my reactions.

I experience constant burning pain (from uncomfortable to very bad) both inside the bladder and down the urethra. I also have a very hard time getting to the bathroom on time.

When I feel as though I have to pee, it's practically impossible to not start going right on the spot. Many times the content is miniscule. I have had many accidents (colossal drag!)and now have tupperware containers in the car! I pee anywhere! I'm also keeping the pad companies in business.

Anyway, my first post treatment cystoscopy is on March 19th, and I am anxious about it.

Is it common for people to experience so much pain and semi-incontinence after more than a month off the BCG?

I have been given pain medicine (PROSED/DS) and something that's supposed to be helping the incontinence (DETROL LA), but neither have helped as much as I'd like.

What do you people think? Is pain/incontinence common this long after the BCG?

Thanks a lot, I always benefit from the information here.

Joana

\*\*\*\*\*

Hi Joana,

I too suffer from regular pain and to a much lesser extent some incontinence after BCG. I began BCG in Nov of 99 and have gone through 15 of these treatments now with #16 coming this week. The treatments I received after surgery were without a doubt the worst. In your case, your tumor was large and no doubt the healing in that area takes longer (more area to be painful). The more time that passes, the better it seems to get. The first series of six kept me near a bottle of Tylenol all the time. I remember I really felt lousy. I find that Tylenol Arthritis helps me the best. Same ingredients as the normal Tylenol, just a bit more of it. My doc told me to stay away from aspirin or ibuprofen. I remember that when I was going through the first series of six my mind always told me to stay away from the Tylenol....that I could get along without it. I would do that until I felt so crummy that I had to take it. When I started taking it three times daily on a regular basis I became much more comfortable. I travel all the time for work and find I have to stop frequently to find a bathroom. This is especially true if I've just had a treatment. All of this is the price I pay to keep my bladder. It is now part of the routine discomforts and irritants of my life. I do still have my bladder and learned just last week after a Cystoscopy and Cytology that I am at least three months away from having another Cystoscopy, Cytology and possibly surgery. So I again received news that I was able to celebrate with one glass of red wine. Now its back to daily doses of green tea and Oncovite, with the hope I can keep this at bay and continue to prevent future recurrences.

I remember you saying you were going to UC San Francisco or Stanford for a second opinion. I'm curious to know how that went, how you were treated there, and if more of your questions were answered there? I have often thought of doing this myself just see if someone else has something different to say about my case.

Take Care.....Dave

\*\*\*\*\*

Aloha Joana..

Hmmmm..although being a man ...I have the exact same symptoms. Omg and the pain lasts till the next instillation of BCG. I try to keep as close to a bathroom as possible ...and I mean really close. I purchased some external catheters and a Foley bag when I'm out in the public ....Hell..I can't sit for 1 min without wanting to pee....I understand that they have cups for females at the medical supply stores.

Most of the bladder group here will be on or have been on Pyridium or

Pyridium Plus...it helps the spasms and the burning. For the pain..I take some over the counter pain meds...and cardinal rule...(although it sounds contrary) drink tons of water and I mean tons ....(it will dilute the BCG and help you pass it ) don't worry the BCG has done its job after the 2 hour limit....

I hope this little info helped ...god bless and keep a stiff upper lip...its

painful but the alternative is a lot worse... again bless

Aloha nui loa

Joseph

\*\*\*\*\*

Hi Joana,

What you have described is common. I had all the same things you are having and more. The BCG leaves your bladder in a very irritated state causing cystitis which can cause the symptoms you describe. I had it for quite a long time after I completed the BCG. I would definitely talk to my doctor about it. The Detrol helped me as did Urised(which turns the urine blue) but I think that time is the best help for it. The irritated bladder lining just has to heal.

Carole

P.S. It also could be a yeast infection, I had those on a regular basis during and after the BCG

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Hi everyone--I'm doing maintenance BCG which I started in January. I had two instillations and had a great deal of trouble with them--bleeding, blood clots, bladder spasms etc. I wrote to Dr. Lamm and he told me to cut back--not to do the 3rd instillation at all and then to continue at 1/10th strength. He said that there was no need whatsoever to suffer like that and it may even be counterproductive. He has stressed to me that there shouldn't be anything but minor discomfort. Perhaps some of you should ask whether the dosage should be reduced instead of enduring all of these side effects.

Barbara

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It is not uncommon for a BCG reaction to last a month when there is an over reaction. In addition, to Detrol get a prescription for Pyridium 200mg (or take 2 100mg). Stop any maintenance treatments until you have no more pain or reaction. See Doctors Lamm's treatment protocol at this site. Dr.Lamm also covers problems if they are more involved.Drink a lot of water, no coffee, spices, liquor, etc.

Tom

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No Reactions After BCG

Hi!

I'd like to say how glad I am that I found the bladder cancer cafe and this list. I was diagnosed with BC in 1993 at 42 and had a tumor removed--not positive but think it was T1. I then had 6 weeks of BCG, then monthly for one year, every 3 months for a couple of years, then every 6 months through January 2000 (after the 1st year the BCG was administered after routine cystoscopies). I went in for my followup cystoscopy in January of this year and a very small recurrence was found. BCG was done and surgery was scheduled. This was removed February 7th and was grade 1. My doctor has recommended monthly BCG for the next year and cystoscopy every three months for the next year. I had the first post-surgery BCG last week.

Now, here are my questions and concerns:

1. I've read Dr. Lamm's protocol and wonder if those would apply to my situation--BCG 1x/weekly for 3 weeks, etc. rather than monthly.

2. Whenever I've had BCG I've experienced some discomfort afterward ranging from pain with the first few voids to some of the flu-like symptoms. I've always found these manageable. What concerns me now is that after the BCG last week I experienced nothing. It's like it didn't happen. I would have expected that there at least would have been some discomfort with the initial void especially since I'd had surgery

just a few weeks before. I might be worrying too much but now I wonder if there was something wrong with the solution. Has anyone else had this experience?

I've arranged to speak to my doctor about these concerns but am very interested in your thoughts. This group has given me more information in a few weeks than I've gotten in years. I've already ordered and received Dr. Schoenberg's book and just got Oncovite in the mail today.

On one hand, I feel very fortunate to have gone 7.5 years before a recurrence. On the other hand, I feel like I'm starting all over. So, I want to be as informed and aggressive as I possibly can be.

Michele

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None of the my BCG treatments have had ANY discomfort at all.....

Gary in Dallas

(Gary's BCG Diary)

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Hi Michele--I had two thoughts on the subject of BCG. Why don't you print out Dr. Lamm's protocol and bring it to your next appointment. Make him (or her) aware that you've been researching the subject and that you'd like to discuss all the treatment options. It never hurts to make your doctor aware that you are an informed patient.



I wouldn't worry about the lack of reaction to the BCG--it's within the range of normal and it's the way we'd all like to respond to it!!

Barbara

\*\*\*\*\*

I forgot what is your type TA, T1 etc? You thought T1? You must find out what type, it effects treatment. Get a copy of your pathology report.

Most of us follow Dr. Lamm's protocol. The once a month BCG has been shown to be no better than the 6 week induction of BCG. Whereas the 3 week BCG maintenance has been shown to be very effective. Have your Doctor look up April 2000 Journal Of Urology, if he is not familiar with Dr. Lamm which I doubt. My doctor also has some patients on the once a month BCG treatment and we go round and round with the research papers. He's starting to become a believer. Bring a copy of Dr. Lamm's protocol with you. The immune system peaks after 3 consecutive treatments not once a month with documentation to support this what does he have to support the once a month. He'll probably

reference the PDR and maybe Ratcliff which Dr. Lamm addresses. Another issue

The journal also covers the vitamins (Oncovite). It must be noted, however, that this is an on going discussion that results in all these different protocols.

Don't worry about no reaction, it happens. BCG should be kept at 40 degrees F. and not exposed to light and used shortly after mixing. If the light doesn't go out in his Fridge the BCG would go bad it would get too hot. This of course would be a long shot, but possible. As you see I'm not very trusting. But 3 weekly treatments are better than once a month for sure.

Also, getting BCG concurrent with a cysto invites problems from cysto irritation which adds to the BCG irritation. I like to keep them separate.

Plus there was a paper stating that the numbing gel could effect the BCG.

Tom

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Dear Tom,

Thank you for your thoughtful comments. Just to clarify, the tumor in 1993 was T1 and grade 2. The most recent "sighting" was T0 and grade 1. I just spoke to my doctor and he feels that since this was so small and that I had gone 7.5 years without recurrence that he wants to stick to a monthly schedule for now. My doctor also reassured me that no reaction to BCG is fine.

Michele

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It's pretty low grade, and it's hard to argue with success.

Best of Luck,

Tom

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