Nothing in this document should replace advice from your healthcare team. Always discuss questions about your diagnosis or treatment with your doctor and follow their advice.

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Last updated 8/24/2026

I (64M) was diagnosed with bladder cancer (BC) in February 2025. I am not a medical person, just a bladder cancer patient. This is not medical advice. This is just information related to what I've experienced myself or have come across while researching bladder cancer.

I created this document to help newly diagnosed patients gain a better understanding of the treatments related to bladder cancer (e.g. TURBTs, cystoscopies, BCG treatments, etc.), provide a collection of links to patient resources and a list of some of the more common drugs available to treat bladder cancer.

I am based in the U.S., so treatment options may vary in your country. Under the section "Resources for Bladder Cancer Patients", I list a few resources for a few countries outside the U.S. If you live outside the U.S. and would like to have links added that are related to bladder cancer treatment in your country, message me on Reddit or reply to the post where you found this document.

My Timeline

- 2/14/25 – I saw very dark urine in the morning (that I chalked up to tea the day before), then light-red-looking urine twice later that day. Urgent care visit resulted in being sent for a CT scan to rule out kidney stones (no stones). However, they saw a small mass in my bladder, which meant going for a cystoscopy ("cysto").
- 2/18/25 – First cystoscopy, performed by a urology PA. The cystoscope clearly showed a small tumor (it looked like a piece of coral).
- 3/13/25 – First TURBT. Two tumors removed. Pathology showed Ta HG NMIBC.
- 4/21 through 5/27 – six rounds of BCG treatment. No bad side effects.
- 7/8/25 – second cysto – 5 tumors seen
- 7/22/25 – second TURBT - (pathology showed Ta LG NMBIC)
- 9/23 through 10/7 – three rounds of BCG treatment (I felt run down the 8th treatment and had lots of blood mixed in with my urine the 9th treatment)
- 11/11/25 – third cysto – 5 tumors seen
- 12/10/25 – third TURBT (pathology report said "no invasive carcinoma is identified", which I think is called NED – **N**o **E**vidence of **D**isease). This is the first (and only time) I was given the chemo drug gemcitabine right after the TURBT. It may be coincidental, but after receiving the gemcitabine after my third TURBT, I've been tumor free.
- 1/13/26 and 1/20/26 – two rounds of BCG treatment. Missed my 3rd round due to weather (twice), so they just scheduled the cystoscopy for 2/24 because it would have been too long of a gap between my 2nd and 3rd instillation.

- 2/24/26 – First clean cysto.
- 6/4/26 –second clean cysto. My oncologist saw about 3-4 flat, light brown areas that he said weren't CIS but could be the start of low-grade tumors, so he zapped them with a laser.
- 7/1/26-7/15/26 – maintenance BCG
- 9/3/26 – cysto (no tumors. That makes nine months tumor free!)
- 9/4/26 – mpMRI (a prostate-specific MRI) – The MRI showed a lesion that would normally be categorized as PI-RADS 4, but given my 14 rounds of BCG, the radiologist felt it was granulomatous prostatis and not cancer.

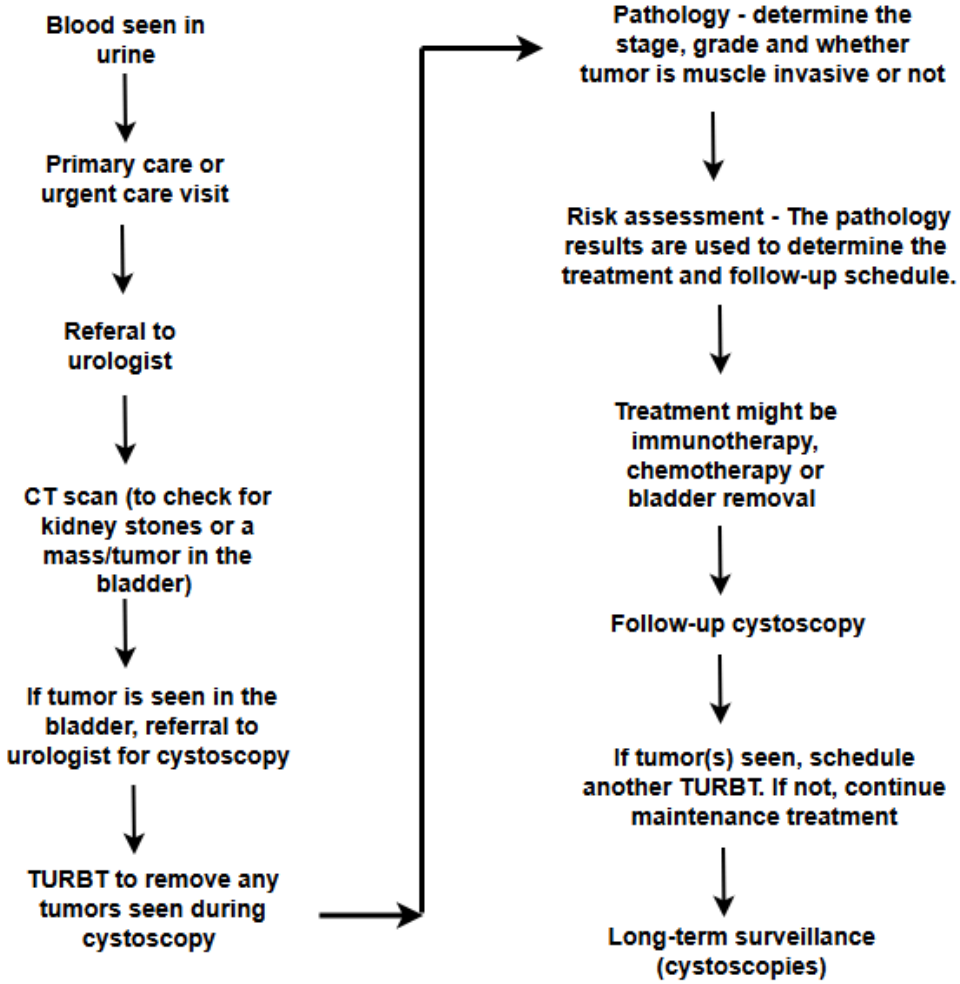
Although bladder cancer has a high recurrence rate, many recurrences are found early and removed before the cancer has had a chance to spread to other parts of the body. This is why your oncologist will schedule you for a cystoscopy every 3-4 months during the first two years of bladder cancer treatment.

It is very common to see new tumors after bladder cancer treatment, whether you're doing intravesical immunotherapy (e.g. BCG) or intravesical chemotherapy (e.g. gemcitabine, Gem/Doce, mitomycin C, etc.). Don't equate recurrence with treatment failure. I had 5 new tumors appear after my first two TURBTs, despite nine rounds of BCG treatment. After 3 TURBTs and 11 rounds of BCG, I finally got a clean cystoscopy (i.e. no tumors seen during the cystoscopy). There's more info on cystoscopies and BCG treatment later in this doc.

Discovering You Have Bladder Cancer

Below is the typical path people go through **before** and **after** they're diagnosed with bladder cancer. While blood in the urine is a common symptom of bladder cancer, there are numerous other symptoms that could be signs of bladder cancer. The link below lists other possible symptoms:

https://bcan.org/facing-bladder-cancer/bladder-cancer-signs-symptoms/



Keep in mind that every bladder cancer patient is different. The treatment your oncologist decides to use depends on the stage, grade, tumor size, number of tumors, whether it's muscle invasive or not, previous treatments and how your cancer responds to treatment.

PSA Check (for men only)

If you haven't had your PSA checked in a while, ask your oncologist if you should get one done before treatment starts. This helps establish a baseline reading before you begin your treatment. It's a simple blood test.

At my physical in April 2025, just before I started BCG treatment, my PSA was at 1.9 (and had been around 2.0 for the previous 9 years). When I had my physical this past April, it jumped to 4.8. That could be a sign of prostate cancer, **but,** many men see their PSA scores jump up when they start BCG. There are several things that can raise your PSA score besides cancer. Those include:

- enlarged prostate (medical term is BPH or benign prostatic hyperplasia)
- trauma to the prostate (e.g. from multiple TURBTs and cystos)
- BCG (and the related trauma from the catheter)

Because my PSA score more than doubled since I was diagnosed with bladder cancer, my oncologist scheduled an mpMRI (a specialized MRI for the prostate) to be on the safe side.

Cystoscopy – What to Expect

If you end up going through the stages outlined in the earlier flowchart, at some point you'll likely be sent to a urologist to have them perform a cystoscopy. This is what a cystoscope looks like (it's not nearly as bad as it looks):

Before they insert the camera, they push lidocaine into your urethra to numb it. They should wait at least 5 minutes to give the lidocaine time to work. Below are a few links that clearly state to wait 5 minutes:

https://pmc.ncbi.nlm.nih.gov/articles/PMC8506429/?utm_source=chatgpt.com

https://www.glydo.com/how-to-use-glydo

How to Use Lidocaine Jelly for Catheterization - Biology Insights

For men, you'll probably feel a little pressure as they pass the scope past the prostate. It was only a little uncomfortable for a second or two, maybe a 2 (max) on the 1-10 pain scale. You can watch the monitor as they move the scope around inside your bladder. It's interesting to watch. They should be looking not only at the bladder walls, but also the two openings to the kidneys (the ureters) and the opening of the urethra (the hole where they entered the bladder).

In some cases, they may also use a laser to hit spots that look suspicious. They do this with the cystoscope still in your bladder. They basically feed a very thin fiber optic filament into an opening in the cystoscope. The light carried by this filament is used to zap the suspicious spots. You typically don't feel anything, but you might feel a very slight "pinch" for a second. Of the five areas I had zapped, I only felt a pinch on one of them. By treating these spots during a cystoscopy, you avoid a TURBT. But of course, if they see areas that are obvious tumors, it results in getting sent to the operating room for a TURBT. There is a small risk of perforating/piercing the bladder when this is done.

The use of a laser to zap suspicious spots is known as laser fulguration or laser ablation of bladder lesions.

The areas he zapped could have been one of the following:

- Small recurrent low-grade tumor areas
- Areas of inflammation or after-effects from prior treatment
- Flat lesions that the physician feels are suspicious and worth destroying

The first few times you urinate after a cystoscopy, you may see just a little blood in the urine and have a mild stinging sensation. If it becomes uncomfortable, consider taking an over-the-counter medication named AZO, but check with your doctor first. Most people are OK taking it. It's a standard medication given to women for a urinary tract infection. **Note:** AZO will turn your urine a bright yellow or orange color.

Cystoscopy Frequency

Your oncologist should follow AUA guidelines when determining how often a cysto should be performed. This is based on whether the cancer is considered low-risk, medium-risk or high-risk. On the link below, start at the heading "Risk Adjusted Surveillance and Follow-Up Strategies":

https://www.auanet.org/guidelines-and-quality/guidelines/bladder-cancer-non-muscle-invasive-guideline?utm_source=chatgpt.com

TURBTs

Prior to your TURBT, you should be provided with some basic instructions about the TURBT through your hospital's web portal. This should include a nurse's triage hotline. This hotline is typically available to call between 8am-5pm M-F for any questions you have after the TURBT. Keep this number handy. This is quicker than messaging your oncologist, especially for something urgent.

In preparation for your TURBT, you might consider having the following available:

- pajamas
- AZO (to lessen the stinging while urinating)
- pain meds
- digital thermometer

Transurethral resection of bladder tumor (TURBT) is a procedure used to diagnose and treat bladder cancer. During a TURBT, an oncologist uses a long, thin tool with a camera on it called a cystoscope. It's inserted through your urethra and into your bladder to allow the surgeon to find and remove any tumor(s) that are present. Most patients are given general anesthesia for this procedure (I have read that some people request regional or spinal anesthesia, which numbs the lower half of the body while allowing the patient to remain awake).

https://my.clevelandclinic.org/health/procedures/turbt

Postoperative Intravesical Chemotherapy Instillation

Ask your oncologist if they are going to give you a postoperative intravesical chemotherapy instillation. This refers to the process of pushing something like Gemcitabine into your bladder immediately after the TURBT. As stated in the link below: "The rationale for postoperative instillation of intravesical chemotherapy includes both destruction of residual microscopic tumor at the site of TURBT and of tumor cells dispersed within the bladder."

https://www.auajournals.org/doi/full/10.1097/JU.0000000000003846?utm_source=chatgpt.com

I didn't receive anything after my initial TURBT or my second TURBT and tumors returned each time. Immediately after my third TURBT, they gave me a dose of gemcitabine that I held for an hour. After that, there were no tumors seen at my next two cystos. I can't say for sure this made the difference, but it seems too coincidental.

Some of the reasons that you may **not** receive postoperative intravesical chemotherapy instillation include:

- suspected bladder perforation
- extensive or deep resection
- significant postoperative bleeding
- high suspicion of muscle-invasive disease
- patient intolerance or allergy

If it was withheld, it's most likely because your oncologist didn't want to take a chance on the chemotherapy leaking outside the bladder and causing serious tissue damage or get into the bloodstream.

White Light vs. Blue Light

White light cystoscopy (WLC) is commonly used during a TURBT. This allows a surgeon to see any visible tumors with the naked eye. The problem with white light is the surgeon can't see very small areas of cancer, cancer that lies flat on the inner bladder wall (known as CIS) or clearly see the edges of the tumor being cut out (resected).

A more recent type of cystoscopy known as blue light cystoscopy (BLC) helps to see cancer hidden from the eye. This type of cystoscopy uses an optical dye named Cysview. When BLC is used, the dye is pushed into the bladder via a catheter an hour prior to a TURBT. The dye is taken up by cancer cells. When the surgeon shines a blue light through the cystoscope, any cells containing the drug will glow in a bright pink color, making the cancer easy to see. This can help the doctor see abnormal areas that might have been missed by the white light. They start with white light and remove any visible tumors, then switch to blue light to remove any cancer that couldn't been seen with white light. BLC is more expensive than WLC and more time consuming.

The article below talks about the BRAVO study and how (in a small group of patients), it showed that those "who underwent blue light cystoscopy had a significantly lower risk of cancer recurrence compared with those who had white light cystoscopy alone."

https://www.curetoday.com/view/blue-light-cystoscopy-reduces-recurrence-in-high-risk-bladder-cancer

What to Expect

Pre-operative Instructions

At least a week before the surgery, you should be provided with instructions to follow prior to the surgery. It's important to take the time to read through them when you receive them, as some instructions are time sensitive. For example, they might tell you to stop taking certain medications or supplements 7-10 days before surgery.

At Duke, I received a phone call from a nurse the **day before** surgery to confirm the time I should show up the next day.

My generic instructions also said the patient should:

- shower the night before and the morning of the surgery with antibacterial soap (e.g. Dial antibacterial soap)
- not apply deodorant, make-up, lotion, perfume or powder to the skin
- not wear contact lenses
- remove all body jewelry and nail polish prior to surgery

Pre-operation

The day of the operation, you'll be asked to arrive a couple of hours before the surgery. This is to give you time to get checked in and get you prepped before the surgery. You will need someone to drive you to and from surgery.

You'll have an opportunity to use the bathroom before they take you into the prep room. The prep room area will look like the pic below. Just a series of small rooms with curtains. This is **not** where they'll be performing surgery.

You'll be asked to strip down completely, put on a gown and socks they provide, then lie on the bed. You might be offered a warm blanket.

The nurse will ask you for basic things like your name, DOB, the procedure you're having done, your doctor's name and any meds you've taken the past 10 days.

Several people will be coming and going for the next 30-40 minutes. For me, this included the head anesthesiologist, anesthetist nurse and my oncologist. The anesthetist will ask a series of questions (e.g. Do you have a pacemaker, ever had a heart attack, any previous problems with anesthesia, etc.). Mine also explained in detail what was going to happen, how they'd be constantly monitoring my heart, breathing, O2 level, pulse and brain waves. She told me I'd be constantly fed anesthesia until the surgery was over. She was very thorough and put me at ease.

At some point, they'll put a needle with a tube into the top of your hand. This allows them to administer any pre-surgery drugs and any necessary drugs during surgery.

Next, they'll wheel you back to the operating room/operating theater and move you from the portable table onto the operating table. Take your time getting onto the operating table and remember there's a needle in your hand. You don't want to flex your hand in such a way that might cause the needle to go further into your hand. It really isn't a problem. Just something to keep in mind.

I was asked if I ever had any problems with a breathing tube and was told I could opt for a mask instead. But they told me they prefer using the breathing tube. It's apparently safer than a mask:

"*General anesthesia drugs relax the natural reflexes that control your breathing, coughing and swallowing. The breathing tube is placed down your throat and windpipe (trachea) after you are unconscious. It ensures that you have a safe passageway for your lungs to receive oxygen and anesthesia medications during your operation. If circumstances permit, the anesthesiologist may use a different breathing tube (called an LMA, or laryngeal mask airway) that does not enter the trachea but still ensures a safe passageway for you to breathe*."

https://www.overlakehospital.org/services/surgery/anesthesia/general-anesthesia

The breathing tube is usually removed just as you are waking up. I had no memory of the tube being inserted or pulled out. Your throat may feel sore or hoarse for a short time as you recover (I had neither soreness nor hoarseness).

Once I was on the operating table, they put a foam device under my neck for support, once again confirmed my name, DOB and the procedure I was having done. Once that was done, the anesthetist said “OK, time to go to sleep”. He mentioned the drug he gave me earlier may make me feel weird, and as he said that, I looked up at the overhead light and within seconds I was out (literally within 3 seconds). The next thing I knew I was waking up in recovery. I recalled nothing from the time I lost consciousness to the time I woke up in the recovery area. It’s a very strange feeling.

Post-operation

It is possible that you could wake up with a catheter in your urethra. One reason for this is if your doctor is concerned there might be bleeding from the tumor that could result in a blood clot in the urethra, preventing the flow of urine out of your bladder. So, out of an abundance of caution, they’ll insert a catheter that will drain into a bag attached to your leg. You might have this in several days.

While in the recovery room, they are going to want to make sure you can urinate before releasing you. It took me probably 30 minutes to feel awake enough to try to pee into a bottle they gave me. If you can’t urinate, they’ll most likely put a catheter in you with a bag strapped to your leg and you’ll have to live with it for a few days.

Despite feeling like I needed to go, I couldn’t get a drop out. I drank more water. Still not able to urinate. The nurse then told me that soda is better at making you urinate, so she got me a small cup of soda. That didn’t help, so I drank one more cup of soda. Shortly after that, I told the nurse I wanted to go to the bathroom because I thought standing would make it easier to urinate. My wife helped me get to the bathroom and I was finally able to urinate. It stung quite a bit, but at least I was able to finally urinate and avoid a catheter. Expect to see the urine a rose color (due to blood from the surgery).

It wasn’t too long after that that the nurse began the discharge paperwork. The needle in my hand was the last thing to come out. They leave that in in case they need to add drugs for any reason.

Many people experience a stinging pain when urinating that starts the day of the TURBT and a day or two after the TURBT. There’s an over-the-counter medicine named AZO that many people use to help reduce this stinging discomfort. It’s typically used for UTIs (Urinary Tract Infections). AZO works by numbing the urethra, which reduces the pain. It definitely helps with the stinging when urinating.

AZO will turn urine a bright yellow or orange color, but you'll still be able to see if there is blood in the urine. The directions say to use AZO for just two days unless otherwise directed by your doctor. Consult with your doctor before taking.

After the TURBT, the urgency and frequency to urinate will be stronger than usual. Because of this, I suggest wearing PJs at least the day of the surgery and a day or two after surgery. This way you're not wasting time unbuckling, unbuttoning and unzipping your pants. And if you must work the day or two after the surgery, stay home. This urgency to urinate after a TURBT isn't nearly as bad as after getting BCG immunotherapy, but there can still be some urgency.

I also had about two weeks of an "ache" when I would first attempt to urinate. It was enough to get me to stop, then immediately try again about 3x-4x before I was finally able to get a stream of urine going. Once the stream started, the pain went away. It was about a three on the pain scale. I'm guessing the pain is from the device passing through urethra (and for men, it could also be related to it passing through the prostate).

It is not uncommon for your oncologist to remove more tumors during a TURBT than what was seen during the initial cystoscopy. This is because the camera used during a TURBT is much more powerful than what's used in a cystoscopy. It can even see a type of bladder cancer known as CIS (carcinoma in situ) that sits flat on the inner lining of the bladder.

Once the tumors are resected (cut out), they are sent to a pathologist who will determine the stage and grade of the tumor, as well as determine if it's **MIBC** (muscle-invasive bladder cancer) or **NMIBC** (non-muscle-invasive bladder cancer). My pathology results took 3-5 days to get back to me.

When they do the resection, they **must** get into the muscle layer to be able to determine if the tumor is muscle-invasive or not. If they don't get into the muscle layer, they're just guessing whether it's muscle invasive or not. MIBC is much more serious than NMIBC. If it gets into the bladder muscle, it has a chance to spread to other organs in your body (known as metastasizing).

Unable to Urinate?

Some people will have problems urinating after a TURBT. It can also happen after BCG treatment, but it's much rarer. People are generally told to go to the ER if they experience:

- Complete inability to urinate
- Severe lower abdominal pain or pressure
- Large clots in the urine
- Heavy bleeding
- Fever or chills
- Signs of possible infection. If BCG gets into your bloodstream, it can cause sepsis, which is life threatening. This rarely happens but is a possibility

If you were given a nurse's hotline during your TURBT or BCG treatment, you can try calling them first for advice, but they are typically only available 8am-5pm.

The standard protocol to resolve the inability to urinate is catheterization, sometimes with continuous bladder irrigation to wash out clots. This would be done at the ER.

The consequences of waiting too long to go to the ER when you can't urinate can be serious. Left undiagnosed or untreated, urinary retention can lead to:

Bladder damage: When urine stays in your bladder, it can overstretch your bladder within hours, causing severe pain and damage to your bladder. It can also lead to long term bladder dysfunction.

Kidney damage: Back pressure can impair kidney function. This pressure can damage your kidneys and lead to kidney disease.

Clot retention: Blood clot retention can worsen and become harder to clear.

UTIs: Urine that stays in your bladder is a breeding ground for bacteria. This can cause infection in your urinary tract that can spread to your kidneys.

Bladder stones: When urine stays in your bladder, it could lead to bladder stones.

https://my.clevelandclinic.org/health/diseases/15427-urinary-retention

Catheter Tips

The following tips were provided by a Reddit user. **Always check with your nurse or doctor if you have questions about these tips.** This is their post (verbatim).

"After being sent home after a TURBT and then going to the ER for a catheter, the experience suggested a few methods to minimize the catheter discomfort. I had a catheter for about six days.

1. Before you leave with a catheter, ask the nurse to demonstrate how to unclasp the StatLock, adjust the velcro leg straps and release the leg bag nozzle.
2. Get a night bag - it's hard to recuperate from general anesthesia when getting up every 2-3 hours.
3. If you go the night bag route, you will need alcohol swabs to clean the male/female nozzles, and clean leg bags to use the next day. You can reuse the catheter bags by rinsing them thoroughly with vinegar and water.
4. KY Jelly - I found this item to be most important in relieving discomfort. Clean the tip of the penis with soap and water and a clean wipe then gently apply KY Jelly at the intersection of the catheter tube and the penis. For me, this made all the difference.
5. When sitting down for an extended time or having a bowel movement feel free to release the StatLock. No more tugging feeling. "

Another user replied to that post saying they applied Neosporin (a topical antibiotic ointment) instead of the KY Jelly.

Second Opinions

If you want to get a second opinion on your tumor pathology (stage, grade, MIBC/NMIBC), look on your pathology report for the number of the lab that did the pathology. If you don't see any info there, reach out to your oncologist and ask them how to go about getting your slides sent somewhere for a second opinion. Your oncologist will not be offended if you want a second opinion on pathology. You must do what's best for you.

Some of the top cancer hospitals in the U.S. are:

Johns Hopkins (Baltimore, MD)

Mayo Clinic (Rochester, MN)

Memorial Sloan Kettering Cancer Center (New York, NY)

University of Texas MD Anderson Cancer Center (Houston, TX)

All the above facilities will charge to stage and grade your slides, but insurance "should" cover at least part of it. Call your insurance company to verify what they'll pay for a second opinion.

I had my TURBT at Duke but decided to get a second opinion on my first pathology. Duke had it down as Ta **HG** NMIBC and UNC (University of NC hospital) came back with Ta **LG** NMIBC.

Nine months after my initial TURBT, I read that the stage helps determine what treatment to start with (e.g. BCG, gemcitabine, etc.) Because of this, I had all the slides from all three TURBTs sent to Johns Hopkins. All slides came back and Ta **LG** NMIBC, so I'm certain now I've had LG cancer all along, but that's not to say it can't advance. And my oncologist did the right thing by treating it as HG based on the first pathology he received.

BCG Treatment – What to Expect

BCG (Bacillus Calmette-Guerin) is a bacterial immunotherapy used to treat bladder cancer. It contains a type of bacteria similar to the one that causes tuberculosis (but weakened).

https://www.cityofhope.org/conditions-cancer-types/bladder-cancer/treatments-survival/bcg-treatment

You should be provided with a package before your first treatment that outlines what to expect from the BCG treatment and what symptoms indicate you need to go to the emergency room. It should also contain a nurse's triage hotline that you can call (typically between 8am-5pm M-F) to quickly ask questions about any symptoms you're having. Make sure you have this info before your treatment and keep it handy. I used the hotline at least twice (once to ask about a lot of blood I was seeing in my urine and another time about blood clots I was seeing in the toilet). When you have an immediate concern, calling this hotline is better than messaging your oncologist and waiting for them (or their PA) to reply.

In preparation for BCG treatment, you might consider having the following available:

- pajamas
- AZO (to lessen the stinging while urinating)
- pain meds
- heating pad or warm blanket for chills
- incontinence pads (e.g. Assurance Men's Guard or a women's equivalent)
- digital thermometer
- Three bottles of bleach. Part of the protocol when purging BCG is to pour two cups of bleach into the toilet before flushing (each time you urinate). The exact details about using bleach are provided later in this document.
- wash cloth/towel/body soap – you'll need to wash your groin area each time you urinate during the 6-hour window described later in the document

There are many bladder cancer treatment options available. See the section titled Newest Bladder Cancer Treatments for some of the most current treatment options available. In this doc, I focus on BCG because (1) it's a very common treatment for high grade non-muscle invasive bladder cancer and (2) it's the treatment that I'm on, so I can speak directly about my experiences with it. Regardless of the treatment your oncologist recommends, ask them **why** they recommend that particular treatment over other treatments. It's helpful to understand the reasoning behind their decision.

BCG is supposed to reduce bladder cancer recurrence and progression. In my case, it took me 11 months, 3 TURBTs and 3 cystos before I finally got a clean cysto (i.e. no tumors seen). I did see my grade go down (HG to LG) after 9 rounds of BCG. But, after each round of BCG, I still saw new tumors.

To hear a good explanation of what BCG is and how it works, watch the following video, starting at timestamp 9:48:

https://www.youtube.com/watch?v=ZNfte-KjV-s

The standard schedule for BCG treatment was established by the Southwest Oncology Group (SWOG). They conducted a trial between 1985 and 1988 to determine the best timing for BCG treatment. The trail is known as the **SWOG-8507 trial**:

https://www.springermedizin.de/seminal-papers-in-urology-maintenance-bacillus-calmette-guerin-b/26353418

This study reported improvement in recurrent free-survival and disease-free survival with the addition of maintenance BCG courses at three months, six months and then six monthly for three years from the start of induction therapy. The dissemination of these findings has formed the basis for international guidelines for BCG maintenance regimens.

I "think" in that last section they are trying to say, "every six months for three years". You can confirm with your oncologist.

If you're interested in a little background on BCG, BCAN.org has a nice document you can read:

https://bcan.org/wp-content/uploads/2018/02/BCG-Expert-Explanation-2.pdf

The link below (on page 3) explains the criteria for when you'd be considered BCG-unresponsive (meaning your bladder cancer is not responding to BCG):

https://www.fda.gov/media/101468/download

> **TIP:** A few days before you start treatment, buy some pet training pads (I use 22"x22"). As you'll find out, the frequency and urgency to urinate is very strong the day of and day after BCG treatment. These pads can help if you can't make it to the bathroom in time. I put four pads down on our couch and car seat. I also layer 4-6 pads under the bottom sheet of my bed (to cover the whole width). I've never had an issue, but it's good to know they're there just in case. Here's an example of the training pads:

https://www.walmart.com/ip/Vibrant-Life-Training-Pads-Large-22-in-x-22-in-50-Count/44856981?classType=VARIANT&athbdg=L1300&from=/search

As mentioned above, the urgency and frequency of urinating the day of BCG treatment (and possibly a day or two after) will be **very** strong. On the day of treatment, you'll be going to the bathroom multiple times an hour for several hours. Expect a slight stinging sensation when you urinate. This typically starts a few hours after you've purged the BCG. AZO (an over-the-counter med) may help with the stinging. And you may only have a few seconds (no exaggeration) to make it to the bathroom. Because of this, I always wear pajamas the day of and day after treatment. I also use Assurance Men's Guard in my underwear in case I don't quite make it to the bathroom on time (which happened a couple of times). The Men's Guard will catch a little bit of urine, but keep in mind these pads are **not** designed to hold a bladder-full of urine. They're designed to catch just a little urine.

If you end up urinating on yourself (i.e. loss of bladder control / incontinence), immediately wash your clothes **by themselves.** Do not wash with other clothes. If you are wearing an incontinence pad, pour bleach on the pad, allow it to soak in, then place it in a plastic bag and toss it in the trash. This is per the AUA guidelines. See section **XV. Patient Education** in the link below:

https://www.auanet.org/about-us/aua-statements/intravesical-administration-of-therapeutic-medication

The "washing protocol" noted above only applies to a six-hour window which starts when they place the BCG into your bladder. More about this later.

You might also have an ache when you start to urinate a day or two after the BCG treatment. I'd rate it no higher than a two on a 1-10 pain scale. It's just enough to make you hesitate a couple of times before you can get the urine stream going. Once the stream started, the ache stopped.

> **TIP:** When you go to the hospital for your BCG treatment, don't completely drain your bladder before you arrive. Why? The nurse has no precise way of knowing when the catheter has reached the bladder other than seeing urine start coming down the catheter drain tube. So, you want a little in there to help them know when the bladder has been reached. I urinate a little at the house just before I leave, then if I still feel the need to urinate when I arrive, I'll urinate a little more but stop short of completely emptying my bladder. The nurse will drain all the urine from your bladder anyway once the cath is in (prior to pushing the BCG into you). This is to make sure your bladder is as empty as possible so that you have the best chance of holding the BCG for two hours.

> **TIP:** If you feel like you need to have a bowel movement the day of the BCG treatment, try to have it before you go. It's difficult to have a bowel movement without releasing any fluid from your bladder. You don't want to have a bowel movement and accidentally release the BCG during the two-hour "hold window" (the amount of time you need to hold the BCG in your bladder).

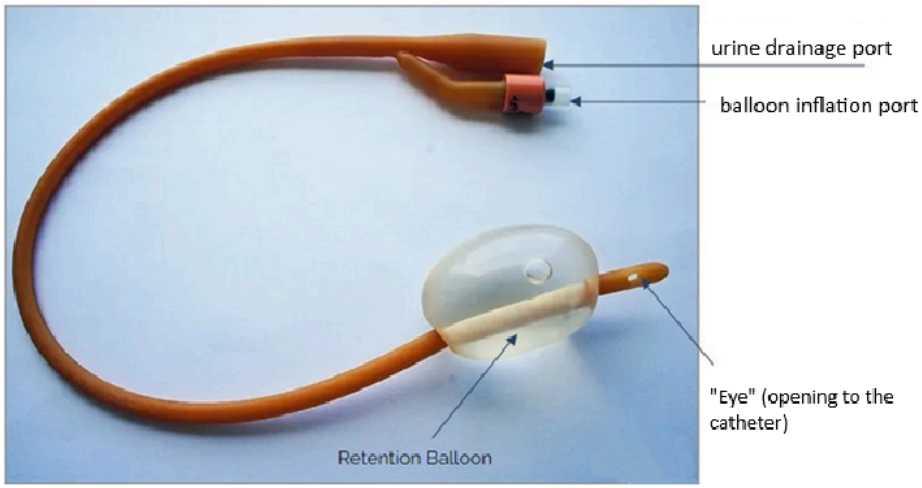
On the day of treatment, when I check in at Duke, I'm given a paper bracelet with a QR code and my name/D.O.B. They scan this ID bracelet 3x-4x during the whole process.

When you're taken back to the room where you'll receive your treatment, ask the nurse what their paperwork says you're there for to confirm you're getting BCG. And ask if it's a full dose (50ml) or half dose. There was a shortage for a long time, and some hospitals still only give half a dose because of the shortage.

Before they put the catheter into your bladder, they will push lidocaine into your urethra. This serves two purposes: (1) it numbs the urethra to make it more comfortable when inserting the catheter and (2) it helps reduce the chances of the urethral sphincter and mucosa from reflexively tightening on the catheter as it's inserted. This in turn lessens the chance of urethral trauma. I didn't have any problem the first eight instillations, but on the 9th instillation, I saw a **lot** of blood in mixed in with my urine two hours after I purged the BCG. I continued to see a lot of blood in my urine for two hours before it finally cleared. After talking with my oncologist about this, he stated the blood wasn't due to the bladder being inflamed from the BCG. He thought it was likely due to the catheter injuring the urethra (even though I wasn't in any pain). For the lidocaine to work properly, the nurse should wait **at least 5 minutes** before inserting the catheter. If they try to do it sooner, just let them know you want to give the lidocaine more time to work. See the Cystoscopy section for links to back up this data.

I didn't find it that uncomfortable when they inserted the catheter. The only point where it was just a little uncomfortable was when it passed through the prostate. It was a very brief discomfort (a little stinging) and very minimal pain (hardly a 1 on the pain scale), and I don't have a high pain tolerance.

Once the catheter is inside your bladder, they use a special device (that attaches to a port in the cath) to inflate a small balloon near the end of the catheter (see pic below). They push 10ml of liquid into the balloon to inflate it (and at the end, they withdraw the solution to deflate the balloon). The balloon helps hold the catheter in place and helps prevent the BCG from leaking past the catheter. **You shouldn't feel any pressure or discomfort as they inflate the balloon. If you do, tell them immediately so they can deflate the balloon, push the cath inside your bladder a little more and reinflate it.** That only happened once out of 14 times I received BCG.



The nurse will not order the BCG from the on-site pharmacist until the cath is in the bladder. This way, in case there are any complications that prevent you from getting the cath put in, they won't waste the pharmacists' time putting the BCG together or waste the BCG. Because of this, you might be lying in bed for 30-45 minutes waiting for the BCG to arrive. It wasn't uncomfortable having the cath in while waiting for the BCG.

For men: They should be using a Coude' (koo' day) catheter. This type of catheter has a curved tip at the end to help get it past the prostate.

Once the cath is in and they bring the BCG into the room, they will be wearing a protective gown and mask to protect themselves from the BCG. They will grab another nurse who will confirm what is being given to you, as well as the dosage being given to you. They'll also verify the info on your ID bracelet again (age and D.O.B.).

The BCG solution must be pushed into the bladder SLOWLY. If it goes in too fast, it can be uncomfortable and cause the bladder to spasm. Each time I had my BCG treatment, the nurse timed it to make sure they weren't pushing it in too fast. They push it in over a 5-minute window.

Once the BCG solution has been administered, the nurse will deflate the balloon by reattaching the device they used to inflate it. **Make sure they deflate the balloon before removing the cath!**

> **TIP:** Do **not** let them leave the catheter in you after they've pushed the BCG into your bladder. I thought it would help keep the BCG in my bladder and asked to have it left in the first time. I stayed in the room the entire two hours my first treatment. Big mistake. After 45 minutes, I had severe bladder spasms. After that first time, once they had pushed the BCG into my blader, I had them remove the cath and went home. No issues with spasms after that.

When BCG is placed into your bladder, the goal is to hold it for one to two hours before purging it. Your oncologist will most likely tell you to try and hold it for 2 hours. Try to hold for 2 hours, but don't consider it a failure if you can't make the full two hours. You're still getting benefit from it. However, if you consistently are unable to hold it at least 90 minutes, let your oncologist know.

AUA guidelines state one to two hours. Look under the heading **XV. Patient Education at the link below**:

https://www.auanet.org/about-us/aua-statements/intravesical-administration-of-therapeutic-medication

Do not hold it in any longer than two hours. There's no evidence that holding it in longer than two hours provides any additional benefit. In addition, holding it longer may lead to worse bladder inflammation, urinary frequency, bleeding and flu-like symptoms. And because BCG is a close relative of the tuberculosis bacterium, holding it longer increases the risk of the bacterium entering the bloodstream and causing sepsis.

In the past, patients were told to lie down and rotate every 15 minutes during this two-hour window. Now, many places (including Duke) no longer suggest doing this. The thought was that by rotating, you'd be coating every part of your bladder. They now say there's no convincing evidence that rotating improves the effectiveness of BCG. Despite that, I rotate every 15 minutes once I'm home. I just feel like it's better to coat the whole bladder. I start face down, then left side, back and right side:

https://www.auanet.org/about-us/aua-statements/intravesical-administration-of-therapeutic-medication

> **TIP:** Begin drinking water **right after** you have purged the BCG from your bladder. I was told to drink 6-8 glasses of water. I try to drink one 10 oz. glass of water every 30 minutes for the first 4-5 hours. The reason you need to drink plenty of water is to (1) clear the BCG from the bladder and (2) help prevent blood clots from forming and blocking the urethra. Continue to drink lots of water the next few days after the treatment as well. **But don't overdo your water intake.** You can cause serious harm to yourself and even die from drinking an extreme amount of water (but you would **really** need to be chugging water to get to that point):
>
> https://my.clevelandclinic.org/health/diseases/water-intoxication#symptoms-and-causes

After several BCG treatments, you might see a lot of blood mixed in with the urine the day of the BCG treatment (and possibly up to 48 hours after the treatment). I saw lots of blood mixed in with my urine after my 9th treatment. It still flowed like urine, but it looked like it was at least 50% blood. That was the only time that happened. If you see a lot of blood mixed in with the urine, call the nurse hotline you were provided and talk to them about it. If you see **just blood** (and no urine) coming out, go to the ER immediately. If you're still within that six hour window where the BCG bacteria is still active, tell the people at the ER that you were given BCG that day and remind them that it contains a bacteria similar to the one that causes tuberculosis. That way, they can take the proper precautions to protect themselves and isolate you when you urinate again (more about this later in the doc).

Urination After Purging BCG

The following is the protocol Duke provided to me. Be sure to follow **your** hospital's guidelines.

- **Go immediately home.** You cannot urinate in a public restroom for the next six hours. The clock starts after they have pushed the BCG into your bladder. The reason for this protocol is that BCG contains a weakened bacteria similar to the one that causes tuberculosis. Urinating in a public restroom would present a health hazard to anyone coming in contact with your urine during that 6-hour window (that's how long the virus is active). Plus, you need to be putting bleach in the toilet (as described below) to kill the virus before flushing during this 6-hour window.
- At home, use a toilet that **only you** will be using for the next six hours. No one else can use that toilet during the 6-hour window.
- **SIT DOWN** every time you urinate for that 6-hour window. This means women **and** men. This prevents urine from getting outside the toilet.

- Wash your groin area with soap and water every time you urinate during the 6-hour window to avoid BCG irritating your skin. I followed that protocol and never had issues with my skin being irritated from it.
- Pour two cups of bleach into the toilet, put the lid down and let it sit for 20 minutes. After 20 minutes, flush (with the lid down).
- Continue this process until the 6-hour window has ended. You must pour two cups of bleach into the toilet each time you urinate.

Duke's protocol didn't say to do this, but after the 6-hour window had ended, I wiped down everything with 409 Spray as well. This includes the toilet lid and seat, toilet handle, any faucet handles I touched, and anything else I may have touched (e.g. a door handle).

Possible BCG Side Effects

Possible side effects from BCG include:

- Chills
- Fatigue
- Urinary frequency/urgency/burning. Urinating 10x in a four-hour window is not unusual
- Blood in the urine or small blood clots
- Low-grade fever
- Joint pain

In reference to the above items, I experienced severe chills one time (treatment #9), and that was the same time I saw a lot of blood in my urine. The chills lasted 1-1.5 hours. My fatigue only lasts the day of and day after treatment (I didn't have any fatigue through at least my initial 6-week instillation). My *urgency* to urinate died down a couple of days after treatment, but the *frequency* to urinate remained higher than usual for about a week, so keep that in mind if you have travel plans soon after your BCG treatment. I've only had a low-grade fever twice and only took acetaminophen one of those times. Sometimes after treatment, I'll have a little ache/pain when I start to urinate. If I attempt to urinate and have a little ache, I usually need start and stop 3x-4x times in a row before I finally get the urine stream going. Once the urine starts flowing, the ache goes away. When the ache occurs, it only lasts about five days and is only a 2 on the 1-10 pain scale.

Joint pain:

It's a bit uncommon, but you might experience joint pain in your knees, shoulders, hips or thighs during treatment. It can be somewhat crippling. I never experienced joint pain until after my 14th instillation.

Leg stiffness and knee pain timeline:

- Six days after my last mBCG treatment (July 21), I woke up with very mild knee pain. By that evening, it had gotten worse and I felt stiffness all around the knees. I felt like an 80-year-old person walking around the house, just shuffling slowly due to the stiffness around my knees.
- July 22 - **Much worse**. I saw obvious swelling above each kneecap, I couldn't bend my legs much at all, it was a struggle standing up off the couch (I had to use my hand to push up off the couch arm to help get to a standing position) and I was shuffling through the house while putting my hand on whatever was available for stability (chair, kitchen

counter, wall). I messaged my oncologist about what was happening. The PA replied and said it could be a delayed effect from the BCG, but they didn't offer anything about addressing the problem. I messaged back late that afternoon, asking what I could do about it. I didn't get a reply that day. I also had a fever of 101.6 that evening, but taking Advil knocked it down to 100 within 30 minutes. When I went to bed, I had to use my hands to help swing my legs into bed.

- July 23 – In the morning, it was just as bad, if not a little worse, so I called the nurse's triage number I was given when I first started my BCG treatment. After talking with the nurse there, they reached out to my oncologist who then prescribed a tapered dose of MethylPrednisolone. I started taking it at noon and laid in bed most of the day. By that night (after taking six 4mg caplets), I was able to swing my legs into the bed on my own. I also started using the walker my wife had used for a foot injury and that helped significantly to get around the house. I had a fever of 101 this morning, but taking Advil knocked it down to 99 in 30 minutes. I had some chills in the afternoon that I resolved by putting a heating pad on my chest and putting a heavy blanket over my legs and torso.
- July 24 - I was able to walk without the walker, but I still had the noticeable swelling above the kneecaps and still had to walk/shuffle around the house, but I was much more stable walking around. And it was **much** easier getting out of a chair or off the couch.
- July 25 – I have much more control when sitting down now, but other than that, no real change. Still moving slowly around the house but was able to get down a few steps to get the mail. No pain killers today.
- July 26 - Had a little hip ache in the early morning in the left hip that resolved by the time I got up. Might be walking a little better today but still feel the tightness/fullness in my legs (but not as bad as it had been). I can control sitting down now and I'm able to get down on the floor for the first time since this started. Still moving slowly due to the feeling of tightness around the knees.
- August 1 - Did my first short hike since the leg stiffness began and did OK.
- August 15 – I've done 3-4 more hikes, each one a little longer and just a little more strenuous (but no more than 40 minutes). Things are feeling much better now but I still can't do a deep squat due to the tightness I feel in my knees when I reach a certain point.
- August 22 – I feel like I'm finally at 100% today. I was able to do an hour hike without feeling any stiffness in my knees. Between roughly August 10 and August 19, I was taking 400mg of Ibuprofen in the morning and at night to help deal with some stiffness that was lingering in my legs. It definitely helped.

Gemcitabine (Gemzar) - Docetaxel (Taxotere) Treatment

I have no experience with Gem/Doce. I've seen several posts on Reddit from people who appeared to have had good results with Gem/Doce. They either started on Gem/Doce or had to switch to it because they could no longer tolerate BCG. The info in this section is taken primarily from the URLs in this section. Other info was taken from Reddit users in the r/bladdercancer sub or Inspire.com.

The standard protocol for Gem/Doce is an initial 6-week induction phase, followed by a monthly treatment for up to two years.

The standard dosage is 1 gm gemcitabine followed by 37.5 mg docetaxel. Both are given with 50mL normal saline.

There is an ongoing clinical trial known as the BRIDGE trial. Its primary objective is to determine the event free survival of BCG-naïve high grade NMIBC patients treated BCG vs Gem/Doc. BCG-naïve patients refer to patients that have never received BCG:

https://clinicaltrials.gov/study/NCT05538663

Dr. Michael O'Donnell (University of Iowa) came up with the idea of combing two existing chemotherapy drugs (Gemcitabine and Docetaxel) to treat bladder cancer.

The group of patients that typically receive Gem/Doce are:

- Those with high-grade NMIBC that recurs or persists after BCG.
- BCG-intolerant patients. These are patients who develop significant BCG toxicity or can't tolerate additional courses.
- BCG-naïve high-risk patients. These are patients that have *never* received BCG.

The original study results from the University of Iowa can be found here:

https://pmc.ncbi.nlm.nih.gov/articles/PMC6218180/

Dr. O'Donnell and Dr. Chakra (University of Iowa) put together the following PDF. It provides tips on how to better tolerate the side effects of Gem/Doce:

https://intravesicaltherapyforbladdercancer.com/hubfs/Treatment%20and%20Tolerability%20of%20GemDoce%20Version%201.2-Feb%202024%20%281%29-1.pdf?hsLang=en&utm

Dr. O'Donnell and his team also put together a website that contains additional info on Gem/Doce, along with other "double chemo" treatments that he's developed:

https://intravesicaltherapyforbladdercancer.com/

Additional links to learn about Gem/Doce are below:

https://www.auajournals.org/doi/10.1097/JU.0000000000002740?utm

The following URL provides a lot of data and tables comparing BCG to Gem/Doce:

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2801788?utm

The following URL contains information from Ohio State University. It includes their protocols for patients being treated with Gem/Doce:

https://healthsystem.osumc.edu/pteduc/docs/GemDocBladderCa.pdf?utm

The following URL contains a section on Gem/Doce:

https://www.urotoday.com/library-resources/bladder-cancer/146299-library-resource-novel-treatment-options-for-bcg-naive-non-muscle-invasive-bladder-cancer-intravesical-chemotherapy.html

The following URL is a short article comparing BCG to Dem/Doce:

https://link.springer.com/article/10.1007/s11255-026-05067-7

The following suggestions came from Reddit users:

- If you have trouble holding either drug, ask for a plugged catheter.
- If you're unable to hold the docetaxel, ask your doctor about taking a sublingual tablet of hyoscyamine before the administration of each drug.
- Stop drinking any liquids 12 hours before each treatment. This will improve your ability to hold docetaxel the recommend two hours and will also keep both treatments from being diluted with urine.
- Refrain from caffeine, alcohol and spicy foods for a minimum of 24 to 48 hours prior to treatment.

Side effects noted in the URLs provided earlier, or from patients on Reddit or Inspire.com:

- Fatigue
- Fever
- Frequent urination
- Blood in your urine
- Brain fog (a.k.a. "chemo brain") - some say ADD meds can help with this
- Pain in the urethra for 12-24 hours
- Severe migraine headaches
- Severe episodes of dry heaves
- Nausea – Ask your doc about taking 4mg Zofran (ondansetron)
- Strong bladder spams - Ask your doc about taking Oxybutynin
- Bladder pain - Ask your doc about taking naproxen (250mg) or Ibuprofen (600mg)
- Hair loss from Docetaxel
- Urine trickling out instead of flowing naturally. Ask your doc about taking Tamsulosin (Flomax).
- Minor bleeding in the first 24 hours after treatment.
- Stinging pain during urination (from the acidity of Gemcitabine) - Ask your doc about taking 1300mg oral sodium bicarbonate the evening prior to and the morning of treatment
- Not being able to fully void.

If you have difficulty tolerating Gem/Doce, see the URL below. It provides two alternative dosing methods for patients:

https://bjui-journals.onlinelibrary.wiley.com/doi/10.1111/bju.16208?utm=

Other Bladder Cancer Tests

Genomic Biomarker Testing

From the link below:

“Biomarker testing is a way to look for genes, proteins, and other substances (called biomarkers or tumor markers) that can provide information about cancer. Each person’s cancer has a unique pattern of biomarkers. Some biomarkers affect how certain cancer treatments work. Biomarker testing may help you and your doctor choose a cancer treatment for you.”

https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment?utm_source=chatgpt.com

ctDNA

For someone with muscle-invasive bladder cancer (MIBC) who has had a radical cystectomy and has no visible cancer on scans, ctDNA (circulating tumor DNA) can be used to look for molecular residual disease (MRD)—evidence that microscopic cancer remains somewhere in the body.

"Patients with muscle-invasive bladder cancer have varied outcomes after cystectomy. ctDNA–based detection of molecular residual disease may identify patients at high risk for recurrence after cystectomy who can benefit from adjuvant immunotherapy, thus sparing patients at lower risk from unnecessary treatment burden."

https://www.nejm.org/doi/full/10.1056/NEJMoa2511885?_sp=d9e5e28d-a088-4b05-a8bf-a08bfafcdc0d&utm

One adjuvant therapy that looks promising is atezolizumab:

https://www.nejm.org/doi/full/10.1056/NEJMoa2511885

https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-atezolizumab-adjuvant-treatment-muscle-invasive-bladder-cancer-patients-molecular?utm_source=chatgpt.com

Additional links that talk about ctDNA are below:

https://blog.dana-farber.org/insight/2026/07/ctdna-guided-immunotherapy-bladder-cancer/

https://pubmed.ncbi.nlm.nih.gov/37330413/

https://www.nejm.org/doi/full/10.1056/NEJMoa2511885?_sp=d9e5e28d-a088-4b05-a8bf-a08bfafcdc0d&utm

Tumor Biomarker Testing

Tumor biomarker testing is also known as:

- molecular profiling
- molecular testing/profiling
- genomic testing/profiling
- next generation sequencing (NGS)

biomarker testing - "A laboratory method that uses a sample of tissue, blood, or other body fluid to check for certain genes, proteins, or other molecules that may be a sign of a disease or condition, such as cancer. Biomarker testing can also be used to check for certain changes in a gene or chromosome that may increase a person's risk of developing cancer or other diseases. It may also be used to help plan treatment, find out how well treatment is working, make a prognosis, or predict whether cancer will come back or spread to other parts of the body":

https://www.cancer.gov/publications/dictionaries/cancer-terms/def/biomarker-testing

Biomarker testing is a key part of precision medicine or personalized medicine. Precision medicine is an approach in which medical care is tailored based on the specific genes, proteins, and other substances in a person's body. *It is often used to see if someone should get treated with certain treatments, such as targeted therapy and immunotherapy*:

https://www.cancer.org/cancer/diagnosis-staging/tests/biomarker-tests.html

Addition links explaining the role of tumor biomarker testing:

https://pmc.ncbi.nlm.nih.gov/articles/PMC11638051/

https://www.urologyjournal.org/article/S0090-4295(19)30345-2/fulltext

https://pmc.ncbi.nlm.nih.gov/articles/PMC11061316/

https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment

Resources for Bladder Cancer Patients

The following organizations are based in the U.S.

BCAN (Bladder Cancer Advocacy Network)

A great resource for people just starting their bladder cancer journey:

https://bcan.org/

Their Bladder Cancer Basics pamphlet has a great overview of many areas related to bladder cancer:

https://bcan.org/wp-content/uploads/2026/02/2026_BladderCancerBasics-FINAL-screen-res.pdf

BCAN also has a treatment matrix. You can use this as an aid when discussing treatment options with your oncologist:

https://bcan.org/treatment-matrix/?utm_source=chatgpt.com

Johns Hopkins Greenberg Bladder Cancer Institute

A nice checklist to take with you to your first meeting with your oncologist:

https://www.hopkinsmedicine.org/-/media/greenberg-bladder-cancer-institute/documents/gbci-question-checklist-final.pdf

NCCN (National Comprehensive Cancer Network)

A helpful brochure from the NCCN (National Comprehensive Cancer Network). They are a National Cancer Institute (NCI)-supported organization that conducts clinical trials in adult cancers:

https://www.nccn.org/patients/guidelines/content/PDF/bladder-patient.pdf

You can find the most recent version of the above brochure by clicking on the link below and enter “bladder cancer” in the search bar. Then look for the link to *NCCN Guidelines for Patients Bladder Cancer*:

https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients

SWOG (Southwest Oncology Group)

Southwest Oncology Group (SWOG) is also a good resource. This is the group that establishes the guidelines for how often BCG treatment should be given:

https://www.swog.org/

AUA (American Urological Association)

The following link provides guidelines for treating NMBIC. For each recommendation, it indicates if it is an expert opinion or a strong recommendation, and what the evidence strength is for that recommendation is. The *evidence strength* rating is A, B, or C. I think with the *evidence strength* rating, they’re trying to indicate how strong the evidence is that **that** particular guideline should be followed. For example, if it’s an A, it’s pretty much agreed upon that recommendation should be followed. Conversely, if it’s a C, there’s still debate about whether that guideline should be followed or not. That’s my interpretation.

https://www.auanet.org/guidelines-and-quality/guidelines/bladder-cancer-non-muscle-invasive-guideline

If you have incontinence (inability to hold/control your urine), they have some pamphlets that might help:

https://www.urologyhealth.org/media-center/bladder-health-awareness-month/bladder-health-month-week-3

Miscellaneous

The following two links have nice images that show the different stages of bladder cancer and how far they reach info the bladder:

https://www.cxbladder.com/nz/patients/bladder-cancer-faqs/stages/

https://healthncare.info/wp-content/uploads/2014/07/Bladder-Cancer-sign-and-sympoms1.jpg

Info on intravesical therapy:

https://www.cancer.org/cancer/types/bladder-cancer/treating/intravesical-therapy.html

The link below is about a company that's trying to find cures for disease by repurposing existing, FDA-approved drugs. The founder's story is amazing (see the second link below). They haven't found a repurposed drug (yet) to treat bladder cancer:

https://everycure.org/ideas/

https://www.youtube.com/watch?v=5K_P5tZMKOs&embeds_referring_euri=https%3A%2F%2Feverycure.org%2F&source_ve_path=Mjg2NjY

Clinical Trials

If your bladder cancer is not responding to any treatment, ask your oncologist to help you find clinical trials that you might be eligible to participate in. Alternatively, you can look for clinical trials yourself by going to the following URL:

> https://clinicaltrials.gov/

Once you enter info into the field labeled "Condition/disease", scroll down and click on More Filters. You can then specify your sex, age and other criteria. Look for trials that are **actively** recruiting**.**

The following organizations are based in Canada

https://bladdercancercanada.org

The following organizations are based in United Kingdom

https://www.fbc.uk.com/

https://www.cancerresearchuk.org/our-research/our-research-by-cancer-type/our-research-into-bladder-cancer

https://www.theurologyfoundation.org/urology-health/bladder-conditions/bladder-cancer/

https://www.birmingham.ac.uk/research/centres-institutes/bladder-cancer-research

https://www.icr.ac.uk/research-and-discoveries/types-of-cancer/bladder-cancer

The following organizations are based in Europe

https://worldbladdercancer.org/bladder-cancer/

The following organizations are based in Australia

https://www.beatbladdercanceraustralia.org.au/

https://www.canceraustralia.gov.au/cancer-types/bladder-cancer

https://www.cancer.org.au/types-of-cancer/bladder-cancer

https://anzup.org.au/what-is-gu-cancer/spotlight-on-bladder-cancer/

The following organizations are based in Ireland

https://mariekeating.ie/cancer-information/bladder-cancer/

https://www.stjames.ie/cancer/typesofcancer/bladdercancer/

Two Types of Bladder Cancer Treatments

Bladder cancer treatments can be broken down into two categories:

- Immunotherapy
- Chemotherapy

With intravesical immunotherapy, the drug that is placed directly into the bladder encourages the body to use its *own immune system* to attack the cancer cells.

With intravesical chemotherapy, a drug is also put directly into the bladder. However, in this case, it is *the drug itself* that actively kills cancer cells. Many of these chemo drugs can also be given systemically (usually into a vein) to treat more advanced stages of bladder cancer.

Source: https://www.cancer.org/cancer/types/bladder-cancer/treating/intravesical-therapy.html

Newest Bladder Cancer Treatments

As noted earlier, BCAN has a treatment matrix you can use as an aid when discussing treatment options with your oncologist:

https://bcan.org/treatment-matrix/?utm_source=chatgpt.com

The following are treatments approved for bladder cancer within the past 3 years (source: bcan.org)

• **TAR-200**

Approved: September 2025

Manufacturer: Johnson & Johnson

Intended use: For adult patients with BCG-unresponsive high-risk non–muscle-invasive bladder cancer (HR-NMIBC) with carcinoma in situ, who are ineligible for, or decline, radical cystectomy. This is a pretzel-shaped device inserted into the bladder that slowly releases Gemcitabine. It stays in the bladder for three weeks before cystoscopic removal.

INLEXZO™

Approved: September 2025

Manufacturer: Johnson & Johnson

Intended use: Indicated for the treatment of adult patients with BCG-unresponsive non-muscle invasive bladder cancer (NMIBC) with carcinoma in situ (CIS), with or without papillary tumors.

Inlexzo is a small, flexible tube shaped like a pretzel that contains the chemo drug gemcitabine. It's put into the bladder through a catheter. It gives off gemcitabine for about 3 weeks, after which it is removed. This allows the lining of the bladder wall to be exposed to the drug for longer than when liquid chemo is put into the bladder.

Inlexzo can be used to treat NMIBC with carcinoma in situ (CIS) that isn't being helped by treatment with BCG. It can be put into the bladder once every 3 weeks for about 6 months, then once every 12 weeks for up to 18 months.

Side effects of gemcitabine intravesical system (Inlexzo): Side effects can include feeling the need to urinate more often, pain or burning when passing urine, urinary tract infection, lowered blood cell counts, and changes in other lab tests.

The tube holding the chemo contains a small metal wire to maintain its shape. Having this in your body could affect your ability to get an imaging test called an MRI, which uses strong magnets. Your doctor will give you an information card to keep with you during treatment.

https://www.cancer.org/cancer/types/bladder-cancer/treating/intravesical-therapy.html

• **ADSTILADRIN** ® (Nadofaragene firadenovec)

Approved: December 2022

Manufacturer: Ferring Pharmaceuticals

Intended use: For adult patients with high-risk Bacillus Calmette-Guérin (BCG) unresponsive non-muscle invasive bladder cancer (NMIBC) with carcinoma in situ (CIS) with or without papillary tumors.

This treatment is made up of a virus that contains the gene to make interferon alfa-2b, an important immune system protein. When the virus is put into the bladder as part of a liquid, it delivers the gene into the cells lining the bladder wall. The cells then start making extra interferon alfa-2b, which helps the body's immune system attack the cancer cells. Because this treatment involves adding a gene to some cells in the body, it can be thought of as a type of **gene therapy**.

The virus used in this treatment doesn't usually cause disease in people with healthy immune systems. It's just a way to get the gene inside the cells. Still, this is a live virus that might cause more serious infections in people who have weakened immune systems. Because of this, this treatment typically isn't recommended for people with a weakened immune system

Adstiladrin can be used to treat NMIBC that is at high risk of returning and that isn't being helped by treatment with BCG. It is typically given once every 3 months.

https://www.urologytimes.com/view/fda-approved-options-for-high-risk-bcg-unresponsive-nmibc

• **KEYTRUDA** (pembrolizumab – "pembro")

Approved: September 4, 2014
Brand name: Keytruda

Intended use: A prescription medicine used to treat a kind of bladder and urinary tract cancer called urothelial cancer. KEYTRUDA may be used alone when your cancer has not spread to nearby tissue in the bladder, but is at high-risk for spreading (high-risk, NMIBC) and when your tumor is a type called "carcinoma in situ" (CIS), **and** you have tried treatment with BCG and it did not work, **and** you are not able to or have decided not to have surgery to remove your bladder.

• **ZUSDURI**™ (mitomycin / UGN-102)

Approved: June 2025

Manufacturer: UroGen Pharma

Intended use: For people with low-grade, intermediate risk bladder cancer that has come back but has not spread into the bladder wall. This is a gel-based form of mitomycin C.

Zusduri is a special form of mitomycin. It is instilled into the bladder as a liquid through a urinary catheter. Once in the bladder, the warmer temperature turns it into a gel that stays in contact with the bladder wall for several hours. Zusduri can be used to treat intermediate-risk NMIBC that has come back after a TURBT. In this situation, it is an option instead of another TURBT, rather than after it. It is typically given once a week for 6 weeks.

Side effects of Zusduri can include trouble urinating, urinary tract infection, blood in the urine, lowered blood cell counts, and changes in other lab tests.

The first link gives a good breakdown of any adverse effects seen during treatment:

https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-mitomycin-intravesical-solution-recurrent-low-grade-intermediate-risk-non-muscle

https://www.onclive.com/view/ugn-102-redefines-treatment-standards-for-low-grade-intermediate-risk-nmibc

• **ANKTIVA** ®

Approved: April 2024

Manufacturer: ImmunityBio

Intended use: For adult patients with BCG-unresponsive non-muscle invasive bladder cancer (NMIBC) with carcinoma in situ (CIS) with or without papillary tumors.

This medicine is an interleukin-15 (IL-15) receptor agonist. When put into the bladder as a liquid, it activates some of the body's immune cells, including natural killer (NK) cells and T cells, which then attack the cancer cells.

Anktiva is used along with BCG to treat NMIBC that hasn't been helped by treatment with BCG alone. Both drugs are typically given once a week for 6 weeks, then less often for up to about 3 years, for as long as they are still helpful.

Opdivo®

Approved: March 2024

Manufacturer: Bristol Myers Squibb

Intended use: In combination with cisplatin and gemcitabine for first-line treatment of adult patients with unresectable or metastatic urothelial carcinoma.

• **Balversa** ®

Full approval: January 2024

Manufacturer: Janssen

Intended use: For adult patients with locally advanced or metastatic urothelial carcinoma with susceptible FGFR3 genetic alterations, as determined by an FDA-approved companion diagnostic test, whose disease has progressed on or after at least one line of prior systemic therapy.

Padcev ® combined with Keytruda ®

Approved: December 2023

Manufacturers: Astellas Pharma (Padcev) and Merck (Keytruda)

Intended use: For patients with locally advanced or metastatic urothelial cancer. The FDA previously granted accelerated approval to this combination for patients with locally advanced or metastatic urothelial carcinoma who are ineligible for cisplatin-containing chemotherapy.

• **IMFINZI** ®

Approved: March 2025

Manufacturer: AstraZeneca

Intended use: Combined with gemcitabine and cisplatin as neoadjuvant treatment, followed by single agent Imfinzi as adjuvant treatment following radical cystectomy for adults with muscle invasive bladder cancer (MIBC).

Other treatments

Gemcitabine and Docetaxel (often referred to as Gem/Doce) are both chemotherapy drugs that have recently been used in combination. Both are administered the same way BCG is, but gemcitabine is put in the bladder first, allowed to sit for a fixed amount of time, drained, then Docetaxel is placed into the bladder and allowed to set a fixed amount of time before being drained. They are now being used in combination to treat patients that are BCG-unresponsive.

These are chemotherapy agents. Gemcitabine works by inhibiting DNA synthesis in rapidly dividing cancer cells, while docetaxel disrupts microtubule function to prevent cancer cell division.

https://www.urologytimes.com/view/fda-approved-options-for-high-risk-bcg-unresponsive-nmibc

HIVEC

HIVEC (Hyperthermic Intravesical Chemotherapy) is a treatment for non-muscle-invasive bladder cancer that involves instilling a heated solution of the chemotherapy drug mitomycin C into the bladder. The heat enhances the drug's effectiveness in killing cancer cells and is used as an alternative for patients who do not respond to standard treatments like BCG therapy.

https://pubmed.ncbi.nlm.nih.gov/38653592/

Your Future After Diagnosis

Once you're diagnosed with bladder cancer, understand that it's a lifelong journey. You might get lucky and have one surgery, be treated with something like BCG and never have to get a TURBT again. But you'll still need at least a yearly cystoscopy at a minimum.

The more times you're tumor free (after a cysto), the longer they extend the recheck for tumors. They might check you (via a cysto) every 3 months the first two years, then every 6 months for two years, then yearly after that. Your oncologist will use established guidelines to determine how often you'll have a cysto and how often you receive treatment. I should point out here that I have read a few posts on Reddit of people going 5 years and even 10 years tumor free, but then new tumors appear. Yes, bladder cancer sucks.

If you're unlucky, you'll have to go through multiple rounds of TURBTs, multiple rounds of treatment and multiple cystoscopies.

If you're very unlucky, you'll need to have your bladder removed (called a radical cystectomy or RC). This is major surgery and life altering. With an RC, you have two options (1) They redirect the ureters (coming from the kidneys) so that urine flows through a hole in the stomach (called a stoma). A collection bag is connected to the stoma and the urine drains into the bag. The bag must be emptied multiple times a day and replaced 2-4 times a week, or (2) you'll get a neo bladder. This is where they take a piece of the small intestine and reshape it into a pouch (to function something like a bladder). The pouch is connected to the ureters (which carry urine from the kidneys) and the urethra (the tube through which urine exits the body). A neobladder has its own set of problems, such as incontinence, not being able to fully empty the neobladder and possibly a need to self-catheterize from time-to-time. If you're considering a neo bladder, have a discussion with your oncologist about self-catheterization. Ask them how often you might need to do this. And consider actually doing a self-catheter in their office so you have an idea if that is something you're willing to do and learn how to do it safely. Not everyone with a neo bladder must do self-catheter, and some people only need to do it for a few weeks after surgery. But this should be part of the discussion with your oncologist if you are considering a neobladder.

The good news for all of us is there have been some really promising new drugs that just came out the past 5 years. See the previous section titled **Newest Bladder Cancer Treatments**.

In addition, Merk (the maker of TICE BCG) is set to open a new facility in Durham, NC in late 2026 that should **triple** production capacity:

https://www.merck.com/stories/addressing-the-global-shortage-of-tice-bcg/

General Tips

Always get a copy of your pathology report to keep with your other records.

Keep a timeline of everything related to your bladder cancer (see a sample spreadsheet at the end of this doc).

Write down your questions and take them with you to your appointments.

Bring someone with you to important appointments. Sometimes it's hard to keep up with all that's being said. Maybe the person you bring with you will remember something you didn't. You can also record the conversation (just ask for permission before doing so).

Don't be afraid to question what your oncologist tells you. This is your life. You need to understand **what** they're doing and **why** they're doing it.

Acronyms

AE - adverse events

BC – bladder cancer

BCG - Bacillus Calmette-Guérin

CFS - cystectomy-free survival. Cystectomy-free survival measures how long patients remain alive without needing their bladder removed.

CR - complete response

CSS - Cause-Specific Survival - the length of time a patient survives without dying from bladder cancer specifically.

DFS - disease-free survival

DOR - duration of response

Gem/Doce – Gemcitabine + Docetaxel (chemo drugs used in combination)

HG – high grade

LG – low grade

mBCG – maintenance BCG

MIBC – Muscle Invasive Bladder Cancer

MMC - mitomycin C (a chemotherapy drug)

NED – No Evidence of Disease

NMIBC – Non Muscle Invasive Bladder Cancer

PFS - progression-free-survival

RC - radical cystectomy. This is the complete removal of the bladder

RFS - recurrence-free-survival

TURBT – Transurethral Resection of Bladder Tumor

Terminology

intravesical chemotherapy - Treatment in which anticancer drugs are put directly into the bladder through a catheter inserted into the urethra. Drugs such as BCG, Gemcitabine and Mitomycin C are placed into the bladder this way.

metastasize – to spread through the body. This is what happens when cancer spreads through your body to other organs. It metastasizes.

adjuvant therapy - treatment after cancer surgery to destroy tiny cancer cells that surgery misses. It may reduce the risk that cancer will come back or spread

BCG-naïve – refers to patients that have never received BCG

Tracking Your Appointments

You will have many appointments related to your bladder cancer. When I was first diagnosed, I decided to create a spreadsheet that highlighted the major events/appointments/procedures I had. I have found this very useful in being able to refer back to various timelines quickly. I also use this to track other health-related things (like flu shot, colonoscopy, etc.).

Below is a snippet of the spreadsheet I created. I even went as far as color coding some things (like cystoscopy in light orange or TURBTs in blue) so I can quickly locate them. You can put in as much or as little detail as you like.

Date	Symptom or Treatment	Notes
2/14/2025	Noticed my urine looked a little pink (twice in one day). No pain or other symptoms.	Went to Duke Urgent Care. Urine culture did not show any growth. No infection. Kidney function was good. Doc said it could be a small kidney stone (even though there's no pain), bladder infection or kidney disease. Doctor referred me to a urologist as a follow-up.
2/16/2025	While urinating, I saw a clump of blood come out.	Returned to urgent. The doctor didn't think it was a kidney stone. She said if I could see it I would have felt it. Still wants me to see a urologist.
2/18/2025		Saw urology PA. She scheduled a CT scan.
2/26/2025	CT scan (with and w/o contrast)	Got a CT scan of the pelvis and stomach to see if anything shows up in the kidneys. Scan didn't show any problems with the kidneys, but it did say (among other things) that "there is an irregular slight hyperdensity along the right base of the urinary bladder containing a few small calcifications.Findings raise suspicion of bladder mass, measuring up to 1.7 cm." Because of this, I scheduled the cystoscopy. Since 2/17 I haven't seen any indication of blood in my urine.
3/6/2025	First cystocsopy when tumor was first seen	Cystoscopy with urololgy PA (my first cystocsopy related to blood in the urine). I could clearly see a growth that looked like a piece of coral. She said I needed surgery to remove the growth and have pathology done.
3/13/2025	First TURBT	Ta HG NMIBC - two papillar tumors - largest was 3cm. Aggregate tumor diameter 3.5cm.
4/21/2025	1st treatment of BCG - had them leave cath in and clamped. They had to release the clamp twice becaue of bladder spasms	able to hold for 2 hours
4/28/2025	2nd treatment of BCG - had them remove cath this time (and all remaining treatments). No more bladder spasms.	able to hold for 2 hours
5/6/2025	3rd treatment of BCG	able to hold for 2 hours
5/12/2025	4th treatment of BCG	able to hold for 2 hours
5/19/2025	5th treatment of BCG	able to hold for 2 hours
5/27/2025	6th treatment of BCG	able to hold for 2 hours

I've embedded the file below if you want to download it. It's only a snapshot of my full medical history.

health tracker.xlsx

Change log:

6/15/26 – Added a section on blue light cystoscopies.

6/17/26 – Added a URL for a bladder cancer organization in Australia

6/20/26 – Minor wording changes. Changed the document title

6/27/26 – Added a paragraph about rotating while BCG is in your bladder

7/1/26 – Added a link to the AUA about rotating while holding BCG and how long to hold it
Added a link for BCAN.org document discussing BCG (at a high level)

7/2/26 – Added a link that explains what BCG-unresponsive means
Added flow chart describing how bladder cancer is diagnosed
Added a snapshot of the spreadsheet I use to track everything related to my bladder cancer.

7/3/26 – Added a section about the SWOG-8507 trial that explains how often patients should receive BCG.

Added comments about why 90-120 minutes is the recommended time to hold BCG and why holding it any longer can cause problems

7/5/26 – Reworded the very top of the document a little bit.

7/9/26 – Minor rewording. Added some additional info about water intake during BCG treatment.

7/11/26 – Added a link to a treatment matrix on BCAN.org's website

7/16/26 – Added a section on possible BCG side effects
Added a section on postoperative intravesical chemotherapy instillation

7/18/26 – Moved the section on urinary retention to the end of the TURBT section
Added a small section about pre-operation instructions
Added a link about other symptoms of bladder cancer (other than blood in the urine)

7/22/26 – Added a note about joint pain being a possible (delayed) side effect of BCG

7/24/26 – Added a note about a nurse's triage hotline for post-TURBT/BCG questions
Added a note about how often a cysto should be performed

7/26/26 – Added three links indicating how long to wait for lidocaine to numb the urethra before inserting a catheter or performing a cysto

8/8/26 - Added a section about clinical trials

8/22/26 – Added a section about Gemcitabine-Docetaxel (Gem/Doce)

8/24/26 – Added a section about MIBC/ctDNA and a section about tumor biomarker testing