

**BLADDER
CANCER**

**PATIENT
GUIDEBOOK**

FOR PATIENTS WITH
NONMUSCLE-INVASIVE
BLADDER CANCER



YOU ARE NOT ALONE



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This Patient Guidebook was created by people just like you – bladder cancer patients and their caregivers. It's designed to offer you support, encouragement and tips on how to deal with the procedures and treatments for your bladder cancer. It can help you understand your disease and what to expect, the treatments you may be offered and how to manage your disease in the years ahead.

We are not medical professionals and you should always turn to your medical team for advice first. But we have been where you are now and have experienced what you are feeling. To ensure accuracy, this Guidebook has been reviewed by a team of medical professionals.

This Guidebook will talk about common approaches to treating nonmuscle-invasive bladder cancer (NMIBC). Keep in mind that there can be some differences, depending on the practices of your medical team and on your specific situation. We will not be using a lot of medical language, except where it might help you better communicate with your medical team and understand your disease. You'll find a handy glossary of terms on Bladder Cancer Canada's website at <https://bladdercancercanada.org>.

Remember, you're not alone. All of us at Bladder Cancer Canada are passionate about helping you to live a full and satisfying life – even after a diagnosis of bladder cancer. We're doing it and so can you.

The birth of this guidebook

What you are about to read is the result of the creative vision of Greg Neely, Vice-President of Bladder Cancer Canada and a bladder cancer patient himself. Greg saw the need for a single source of information written from the viewpoint of Canadian bladder cancer patients and their caregivers. He wanted it clear, simple, and easy to understand – that's Greg's style.

NONMUSCLE-INVASIVE BLADDER CANCER

Many of us never knew bladder cancer existed before our diagnosis. But, it's more common than you might think, as it's the 5th most common cancer in Canada.

Approximately 75% of bladder cancers is the type you have – nonmuscle-invasive. We hope it never happens, but you should also be aware that about 20% of bladder cancer that was originally diagnosed as nonmuscle-invasive, progresses to muscle invasive. Bladder Cancer Canada also has a Patient Guidebook available for muscle-invasive bladder cancer (MIBC).

WHAT CAUSES BLADDER CANCER?

As with many types of cancer, one of the leading risk factors of the disease is smoking. Those who smoke may be up to four times more likely to get bladder cancer. People who work with certain chemicals may also be at risk – leather workers, hairdressers, mechanics and painters, among other occupations. Exposure to radiation has also been linked to bladder cancer. Caucasian men may also be at greater risk.

But the simple truth is that many will develop bladder cancer for no known reason. You may be one of those people. At this point, asking “why” is not nearly as helpful as focusing on “what now.”

HOW IS BLADDER CANCER DIAGNOSED?

The earlier bladder cancer is diagnosed, the better the outcome of treatment. Since there is no “screening” test for bladder cancer at this time, most people are diagnosed after they show some symptoms, such as blood in the urine. Because symptoms such as blood in the urine can be a sign of other conditions, such as a urinary tract infection (UTI), there can be a delay in diagnosing bladder cancer.

Here are some of the tests and procedures used to detect bladder cancer. Please note that, since individual cases and facilities are different, not all of these tests may be required or available.

Urine cytology – a sample of urine is examined under a microscope to see if there are any tumour cells in the urine.

Cystoscopy – a hollow tube with a lens is inserted through the urethra (the tube which drains urine from the bladder) and slowly moved into the bladder, so that doctors can examine the lining of the bladder for tumours. This is the main way bladder cancer is detected. The procedure can be done in a doctor's office or hospital setting. Most often a local anesthetic is used to numb the urethra, but sometimes the procedure is done as an outpatient with sedation.

Transurethral resection of bladder tumor (TURBT) – a surgical procedure through the urethra done in a hospital setting under general or regional (your anesthesiologist injects medication near a cluster of nerves to numb only the area of your body that requires surgery) anesthesia in a hospital setting, to biopsy any abnormal tissue that is found during a cystoscopy. During the TURBT, the doctor will remove tumours and samples of the bladder muscle near the tumours. The material removed is sent to a lab for analysis under a microscope. The result of the analysis is used to help determine the stage and grade of the bladder cancer. (See the following section on “Staging and grading your bladder cancer.”)

Another procedure often done during the TURBT is called EUA (exam under anesthesia). In this procedure, the urologist evaluates the bladder to see if any masses can be felt.

In some facilities, Cysview (hexaminolevulinate HCl) with blue light cystoscopy may be used during the TURBT procedure. A solution containing the hexaminolevulinate HCl (called an “agent”) is inserted into the bladder about an hour before the TURBT. The agent essentially “marks” the tumour, which can be more clearly seen using a blue light. The procedure is designed to enhance detection and visualization of nonmuscle-invasive bladder cancer, in particular carcinoma in situ (CIS) to help ensure the resections (surgical removal) of all suspicious lesions. It reveals lesions that may not be seen with standard white light cystoscopy. Note that Cysview is not available in all medical facilities.

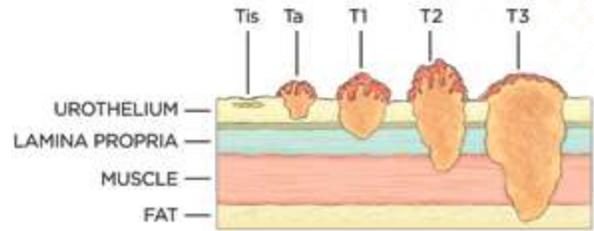
Scans - to help detect if the cancer has spread and to help with staging, the medical facility may use a scan. Depending on the facility and disease status, “Computed tomography” (CT or CAT) scan, “Magnetic resonance imaging” (MRI), or a “Positron emission tomography” (PET or PET-CT) scan may be used.

Ultrasound - uses sound waves to create a picture of the internal organs. It can help find out if the kidneys or ureters are blocked.

After diagnostic tests are done, your doctor will review all of the results with you. If the diagnosis is cancer, these results also help the doctor describe the cancer. This is called staging and grading, which is described in the next section.

STAGING AND GRADING YOUR BLADDER CANCER

Laboratory analysis of the material taken out during the Transurethral Resection of Bladder Tumour (TURBT) is used to determine the type and stage of the cancer. According to the Canadian Cancer Society, staging classifies a cancer based on its extent in the body.



STAGING

Tis - Carcinoma in situ, sometimes call Cis.

Ta - Non-invasive papillary carcinoma.

T1 - The tumour is in the first layer of the bladder lining, but not the surrounding muscle.

T2 - The tumour has grown into the muscle. In stage T2a, the tumour is in the inner half of the muscle layer and in stage T2b, the outer half.

T3 - The tumour has spread to the fatty layer around the bladder muscle. T3a describes a microscopic tumour and T3b a large tumour that can be seen or felt.

T4 - The tumour has spread to organs outside the bladder (T4a) or to the wall of the abdomen or pelvis (T4b).

Nonmuscle-invasive means that the tumour has not invaded the muscle of the bladder (muscularis propria). It has grown into the layer of cells that line the bladder (transitional epithelium) and perhaps into the connective tissue below (lamina propria). The early stages of nonmuscle-invasive bladder cancer are typically referred to as Tis, Ta and T1 on the pathology report.

GRADING

In addition to showing what stage your cancer is, the pathology report following your TURBT will also generally show whether your tumour is “high grade” or “low grade.” Low grade tumours are less likely to spread and invade the muscle than high grade tumours.

TREATMENT OPTIONS



Your doctor may prescribe some of the following treatments to help prevent the cancer from recurring.

TREATMENT WITH BCG

Once the bladder has healed from your diagnostic TURBT, a second TURBT may be performed within about six weeks if the tumour was aggressive. A drug called BCG (Bacillus Calmette-Guérin) may be inserted into your bladder through a catheter once a week for about six weeks (intravesical therapy).

BCG is a weakened form of the tuberculosis mycobacterium which stimulates immune responses within the bladder to destroy the cancer cells.

You'll hold the BCG inside your bladder for up to two hours. Medical facilities have different treatment protocols, but you may be asked to spend time lying down and perhaps rolling on each side and front and back to ensure the chemical makes contact with the whole bladder lining.

Maintenance treatments of BCG may be prescribed to reduce the risk of the tumour recurring. This often involves a three-week treatment plan every three to six months for up to three years.

The initial treatments usually produce few if any side effects, but as the treatments progress, you may experience burning when urinating, a sense of urgency to urinate or the need to urinate more frequently. Some people report fatigue and a mild fever, achiness and nausea. There can be severe reactions, such as pain, inflammation and bleeding, but these are not the norm and diluted or reduced amounts of BCG can be given to help combat these side effects.

TREATMENT WITH MITOMYCIN C

The Mitomycin C treatment you may have had during your TURBT may be continued with a six-week course of treatment, much like the BCG schedule.

The side effects of Mitomycin C treatments are very similar to those experienced with BCG treatments.

ELECTROMOTIVE DRUG ADMINISTRATION (EMDA)

EMDA uses an electrical current to deliver BCG or Mitomycin C into the wall of the bladder. Clinical trials have shown that EMDA may get more of the drugs into the cells of the bladder wall, to further reduce the risk of the cancer coming back.

A small electrode is inserted into your bladder through a catheter. Your bladder must be empty and you will have an ultrasound scan to check. The doctor then washes out your bladder with sterile water and sticks two patches on to your skin, on the lower part of your abdomen. The patches also contain electrodes.

Your doctor attaches the wires from the electrodes to a small generator. The drug is inserted into your bladder through the catheter and the generator is turned on. A small electrical current passes through the patches. The electrical current draws the drug into the cells of the bladder lining. You may have a small tingling feeling but it isn't painful. You have the treatment once a week for 6 weeks. Each treatment lasts for about 30 minutes.

Side effects can be similar to BCG and Mitomycin C treatments. You may also have irritation to skin where the electrodes were attached.

ADDITIONAL TURBT PROCEDURES

In some cases, a follow-up cystoscopy will discover that new tumours have grown in the bladder. Additional TURBT procedures may be done and new rounds of drug therapy scheduled. It is possible to have a number of TURBT procedures over time if tumours continue to appear.

TREATMENT OPTIONS (CONTINUED)



DEVELOPMENT OF NEW PROCEDURES

Research into bladder cancer and its treatment is ongoing around the world, including studies into:

- Changes in the genetic material of bladder cancer cells
- Newer tests looking for substances in the urine that may indicate the presence of bladder cancer
- Ways to reduce the recurrence and spread of bladder cancer
- New surgical techniques
- New drug therapies
- Gene therapy

A good outline of current research is available on the American Cancer Society website at <https://www.cancer.org/cancer/bladder-cancer/about/new-research.html>.

CLINICAL TRIALS

In addition to the therapies approved by Health Canada, you may be able to access other bladder cancer therapies through a clinical trial.

A clinical trial is a research study that tests how well a new medical approach works in people. Each study answers scientific questions and tries to find better ways to prevent, screen for, diagnose, or treat a disease such as bladder cancer. By participating in a clinical trial, you'll be helping researchers answer important questions that will further the development of new effective treatments. Clinical trials may also provide you with another option in your treatment plan.

Clinical trial websites will help you find clinical trials that may be available in your area. Here's one website you can check: www.canadiancancertrials.ca. This site lists Canadian trials only. You can narrow your search by selecting bladder cancer under 'Select a Cancer Type'. You may need to select "Show More" if bladder cancer does not display on the list you see. You can also search by province, city or trial centre.

It's very important that you discuss with your medical team whether a clinical trial is right for you.

BE ALERT



With any medication or treatment, if serious concerns arise you should seek immediate medical attention. You'll want to keep your doctor aware of how you respond to treatments and be prepared to take additional medication if major side effects are a problem. Do not skip treatments without your doctor's approval, since the side effects may be minor compared to the benefits of taking the medication.

It may help to call someone who has had the same treatment. Bladder Cancer Canada can put you in touch with someone who has been on the same journey you are on. Simply call or email us.

A LIFETIME OF CHECKUPS

Of course, it's a great relief to hear your doctor say the words "all clear" after your first post-operative cystoscopy. However, that's not the end of this chapter of your life. Your doctor will tell you how often cystoscopies should be repeated. Every three months is typical for the first two years following an "all clear" to ensure early detection should the cancer come back.

With careful attention to your lifestyle, you can live a healthy life. Be encouraged. Be diligent. And choose to help someone else who faces this diagnosis to look ahead with a positive attitude.

WHERE ELSE CAN I GET INFORMATION?



The Bladder Cancer Canada website (www.bladdercancercanada.org) has a wealth of information, including links to other reliable websites.

The Internet provides lots of information, some of it accurate and helpful and some inaccurate and anything but helpful. However, many world-class cancer centres provide information on line that may help you. But the best source of information in your specific case is your own medical team.

If you are uncertain about your doctor's advice, you are entitled to a second opinion. Please speak to your family doctor or Bladder Cancer Canada about who you can be referred to.

HOW CAN I HELP OTHERS?

Each September, in many cities across Canada, Bladder Cancer Canada organizes Awareness Walks. The walks allow us to tell Canadians about this common cancer. Walk participants can also collect sponsors to raise much needed funds which provide support, spread awareness and aid in research. You can walk, raise money among your family and friends, or volunteer to help coordinate the day's activities at your local walk.

SPREAD THE WORD

Tell your friends, family and healthcare providers about bladder cancer and Bladder Cancer Canada. You can also speak with others who are on this journey with bladder cancer and prove to be an encouragement and a lifeline to them.

To find out how you can help - or to get help yourself - go to the Bladder Cancer Canada website at www.bladdercancercanada.org. Our website has excellent and reliable discussion forums where you can ask questions or share. You can also sign up for our newsletter to stay up-to-date on upcoming events or research news.

We wish you every success in your journey with bladder cancer. Let us know how we can help you. That's why we are here!

HELPFUL WEBSITES:

- **Bladder Cancer Canada**
<https://www.bladdercancercanada.org>
- **Johns Hopkins**
<http://urology.jhu.edu/bladder/>
- **Canadian Urological Association**
<http://www.cua.org/>
- **Mayo Clinic** - <http://www.mayoclinic.org/diseases-conditions/bladder-cancer/basics/definition/con-20027606>
- **Bladder Cancer Advocacy Network (BCAN US)** - <http://www.bcan.org/>
- **National Cancer Institute (US)**
<http://www.cancer.gov/cancertopics/types/bladder>
- **Cleveland Clinic** - <http://my.clevelandclinic.org/urology-kidney/diseases-conditions/bladder-cancer.aspx>
- **Canadian Cancer Society** - <http://www.cancer.ca/en/cancer-information/cancer-type/bladder/bladder-cancer/>
- **Cornell Urology**
<https://urology.weillcornell.org/bladder-cancer>

ABOUT BLADDER CANCER CANADA

Bladder Cancer Canada was formed in 2009 by bladder cancer survivors. We are a national charity with a mission to:

- Help bladder cancer patients and their support teams address the day-to-day issues of this disease
- Increase awareness of bladder cancer among the general public and medical community
- Fund research which pursues the diagnosis, treatment and elimination of bladder cancer.

Bladder cancer awareness among Canadians is at a relatively early stage. There is little public awareness of the symptoms of the disease and, unless diagnosed with this cancer, most people are not well educated about it.

Bladder Cancer Canada creates awareness about this cancer since an early diagnosis usually results in a better outcome.

For more information, visit www.bladdercancerCanada.org.

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You can also follow us on

 [/BladderCancerCanada](https://www.facebook.com/BladderCancerCanada)  [/BladderCancerCA](https://twitter.com/BladderCancerCA)
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SPECIAL THANK YOU NOTES

We'd like to thank those who took part in the production and review of this Guidebook: Greg Neely, Jack Moon, Ieva Fraser, Ed Moffat, Elizabeth Moffat, Valerie MacLeod, Kyle McKenna and David Guttman.

The project manager and editor of the Patient Guidebook series is Stephen Wilson.



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We are grateful to AstraZeneca, Merck and Roche, whose generous financial support has made this guidebook possible.

