

# BLADDER CANCER PATIENT GUIDEBOOK

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BLADDER PRESERVATION  
STRATEGIES FOR MUSCLE-INVASIVE  
BLADDER CANCER



**BLADDER  
CANCER  
CANADA**



## WHAT'S IN THIS GUIDEBOOK?

What causes bladder cancer? . . . . .	3
Muscle-invasive bladder cancer . . . . .	3
Staging and grading your bladder cancer . . . . .	3
Grading . . . . .	4
Treatment Options . . . . .	4
Who qualifies for TMT? . . . . .	4
The partial cystectomy option . . . . .	5
Radiation . . . . .	5
Chemotherapy . . . . .	6
Transurethral Resection of Bladder Tumour (TURBT) . . . . .	6
Side Effects of Treatments . . . . .	6
Chemotherapy . . . . .	6
Radiation Therapy . . . . .	6
Clinical Trials . . . . .	6
Emotions . . . . .	7
Where else can I get Information? . . . . .	7
What can I do? . . . . .	7



# YOU ARE NOT ALONE

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 treatment approaches for muscle invasive bladder cancer (MIBC) that can preserve the bladder. 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.**

## 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.”

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.

## MUSCLE-INVASIVE BLADDER CANCER

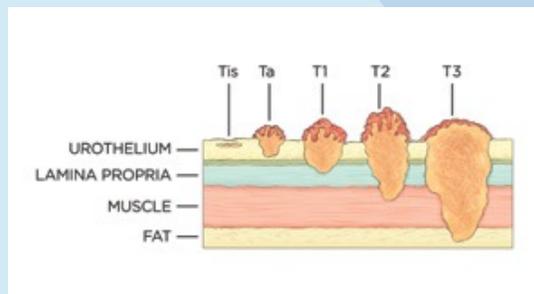
Approximately 25% of bladder cancers are muscle-invasive. It means that cancer tumours have grown through the lining of the bladder into or through the bladder muscle. In most cases, this type of cancer is treated through surgery to remove the bladder completely (called a “radical cystectomy”) and to create a new path for urine to leave the body.

However, you and your medical team have decided to treat your bladder cancer using approaches that can preserve the bladder. There could be many reasons for not using surgery to completely remove the bladder. If you’re older, your urologist may feel that surgery is too risky, you may have other health issues that increase the risk from surgery, or you may have personal reasons for not wanting this major surgery.

This Patient Guidebook will explore the alternatives to radical cystectomy in more depth. First, it’s important that you understand the staging and grading of your bladder cancer.

## STAGING AND GRADING YOUR BLADDER CANCER

Laboratory analysis of the material taken out during your transurethral resection of bladder tumour (TURBT) is used to help 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 (flat tumour), sometimes called 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).

Bear in mind that it can be somewhat difficult for your medical team to know the true extent of your tumour without surgery. That’s because there may be a difference between “clinical staging” and “pathological staging.”

The TURBT is part of the “clinical staging” process, which is done before treatment. Clinical staging also includes a physical exam, imaging tests (such as a CAT scan), laboratory tests (such as blood tests), and biopsies (such as those done following the TURBT).

A cancer can be further staged by examining the material removed during a radical cystectomy. This process is called “pathologic staging.” Complete staging combines the results of the clinical staging with the surgical results. Since you will not have this surgery, your medical team will rely on clinical staging.

## GRADING

In addition to showing what stage your cancer is, the pathology report following your TURBT will generally show whether your tumour is “high grade” or “low grade.” A higher-grade cancer may grow and spread more quickly and may require immediate or more aggressive treatment. Your diagnosis of muscle-invasive bladder cancer may be based on the finding of high-grade tumours.

## IMPORTANT

Keep a copy of the pathology report, which will tell you the stage and grade of your tumour.

## TREATMENT OPTIONS

Although complete removal of the bladder for muscle-invasive bladder cancer has been the “gold standard” for many decades, it’s now accepted that bladder preservation is a safe alternative for carefully-selected patients.

The bladder-preserving approach to the treatment of muscle-invasive bladder cancer is usually a combination of three treatments – radiation therapy, chemotherapy and complete TURBT. The combination of these three treatments is called “trimodal therapy,” which we’ll call TMT for the rest of this Guidebook.

As you’re probably familiar with the TURBT, which you would have had during diagnosis, we won’t explain this treatment here. In a moment, we’ll talk a bit more about radiation and chemotherapy, but let’s start by discussing whether you may qualify for TMT or a partial removal of the bladder.

### Who qualifies for TMT?

Not every bladder tumour is suitable for TMT. Your medical team will help you make a treatment decision to determine what is best for you, based on several important factors.

Radiation is less effective if the bladder tumour is too bulky. This means that TMT is not recommended if it measures more than 5 cm (about 2 inches), can be felt by the physician during a physical examination, or if the tumour causes blockage of urine flow from one or both kidneys (called “hydronephrosis”).

Radiation is also less effective if there are cancer cells in multiple areas of the bladder or if they’re associated with areas of “carcinoma in situ” (a cancer stage called Cis or Tis). These are flat tumours (see the illustration on page 3). This is because of the increased risk of recurrence of the cancer.

It’s also important that you have good bladder function before starting TMT. If you have a lot of problems with frequent and urgent urination, TMT might not be suitable.

In up to 25% of patients, cancer remains in the bladder despite TMT. In this case, complete removal of the bladder is then required and a path to divert the urine to the outside of the body is created.

If complete removal of the bladder is needed, the option for a “neobladder” would not be recommended. This is because radiation delivered during TMT can affect the small bowel and the area of the sphincter (the valve that opens and closes to allow urine to leave the body), even with the best choice of dose and targeting. As a result, there is an increased risk of incontinence, although some patients who receive a neobladder even after radiation can be continent.

Please see our *Patient Guidebook for Patients Facing Radical Cystectomy* for information about neobladders and other urinary diversion procedures. It's available for download from the Bladder Cancer Canada website ([www.bladdercancercanada.org](http://www.bladdercancercanada.org)).

## The partial cystectomy option

We should mention at this point that there may be an option for a small number of patients in very specific situations to remove only a part of the bladder (called a “partial cystectomy”). While removal of part of the bladder has the normal risks associated with surgery, it preserves urinary and sexual function and avoids the need to replace the bladder with a section of bowel.

The bladder is roughly triangular in shape. There is a “roof” or “dome” at the top of the bladder, and side walls tapering down to the “neck” where urine leaves the body through a tube called the “urethra.”

Partial cystectomy is generally considered only in carefully-selected patients with a single tumour located on the dome or high up on the side walls, in particular those with a rare form of bladder cancer called “adenocarcinoma,” a type of cancer that begins in the cells that produce mucous.

The tumour should not be greater than 3 centimeters (just over 1 inch), and there should be no “carcinoma in situ” (a cancer stage called Cis or Tis). These are flat tumours (see the illustration on page 3).

You should have good bladder capacity if you're being considered for partial cystectomy. The normal capacity of the bladder is 400 to 600 millilitres (about 14 to 21 ounces).

## Radiation

Radiation therapy uses high-energy radiation (most commonly x-rays) to shrink tumours and kill cancer cells. Radiation kills the cancer cells by damaging their DNA. Cancer cells whose DNA is damaged beyond repair stop dividing or die. When the damaged cells die, they are broken down and eliminated by the body's natural processes.

While radiation therapy can also damage normal cells, your medical team will take potential damage to normal cells into account when planning a course of radiation therapy. Doctors know how much radiation normal tissue can safely receive. They use this information to help decide the extent and dosage of radiation.

In some cases, your radiation team may first implant a “fiducial marker” into the bladder. This is an object (or sometimes a special liquid) that is visible on scans of the bladder, and may help more accurately define and target the tumour site. This is called “image-guided” radiotherapy.

Radiation therapy is given in the hospital radiotherapy department as a series of short daily treatments. You can usually have it as an outpatient. Each treatment takes 10 to 15 minutes, and is usually given Monday through Friday, with a rest on the weekend. A course of radiotherapy for bladder cancer may last four to seven weeks.

You may have chemotherapy before or during the course of radiotherapy, or both, to help make the radiotherapy more effective. See the “Chemotherapy” section for more information.

External radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, after each treatment session.

Side effects vary widely and your doctor will discuss them with you. Be sure to report any side effects that you may have to your doctor as soon as possible, as there are treatments that may help. See the “Side effects of treatments” section for more information.

In the years following radiation therapy, patients need to be followed closely – both for the possibility of recurrence in the bladder that might require surgery, but also because a few patients might develop bladder or bowel complications because of the radiation.

## Chemotherapy

Chemotherapy (or “chemo”) uses drugs to destroy cancer cells. In this sense, chemotherapy has the same effect as radiation therapy. Some chemotherapy drugs are given on their own or several chemotherapy drugs may be given together.

Certain chemotherapy drugs have been shown to make the cancer cells more responsive to radiation therapy. For this reason, radiation therapy and chemotherapy are often done together (called “concurrent” or “concomitant” therapy). In some cases, chemotherapy is given over several weeks before radiation treatments start (called “neoadjuvant”).

Combining radiation and chemotherapy offers you the best chance of killing the bladder cancer cells in your body.

Most chemotherapy drugs are put right into your bloodstream through “intravenous” or “IV treatment.” Each treatment can last from a few minutes to a few hours.

As with radiation therapy, chemotherapy can have side effects, which you should discuss with your doctor. Side effects vary widely and treatments are often available for any side effects that you may have. See the “Side effects of treatments” section for more information.

## Transurethral Resection of Bladder Tumour (TURBT)

When you’re having bladder preserving therapy, you may need a repeat TURBT to remove as much of the bladder tumour as possible before starting chemotherapy and radiation.

TURBTs may be repeated as treatment progresses to remove any additional tumours that have grown. These tumours are identified using “cystoscopies” (the process of inserting a tube through the urethra and using a small camera to see inside the bladder), which you likely have also had previously.

## SIDE EFFECTS OF TREATMENTS

Side effects can occur with any type of medical treatment, but not everyone has them or experiences them in the same way. Although not pleasant, side effects have to be weighed against the benefit of reducing or eliminating your cancer.

## Chemotherapy

Side effects of chemotherapy will depend on the type of drug used and the dose, how the drug is given and your overall health. They can happen any time during or after chemotherapy. Most side effects go away when chemotherapy is over, although some side effects may be longer-lasting or even permanent.

Some of the most common side effects of chemotherapy drugs are fatigue, nausea, changes to blood cell counts (increasing the risk of infection), loss of appetite, effects on bowel movements and urination, and hair loss. It’s important to let your medical team know of any side effects that you experience, because many of them can be treated. And, hair usually grows back after treatments have stopped.

## Radiation therapy

Some of the more common side effects of radiation therapy are fatigue; effects on urinary function, such as frequency, urgency, mild burning sensation while urinating; and effects on bowel movements. The side effects mostly go away after treatments end, but radiation may have some longer-term effects on bladder and bowel function.

Again, it’s important to discuss any side effects with your medical team, as they can suggest ways to ease them.

## 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](http://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.

## EMOTIONS

Your emotions can best be described as “a rollercoaster.” That’s perfectly normal – after all, you’ve been diagnosed with cancer. It helps to have supportive family and friends around you. Don’t be afraid to express your emotions by talking to others who’ve gone through what you are.

Contact us at Bladder Cancer Canada and we can put you in touch with someone. Our contact information is on the back cover of this Guidebook.

Focus on your task – recovery and creating a new lifestyle. Remember, your positive attitude will be a key element in your recovery.

## WHERE ELSE CAN I GET INFORMATION?

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

The Internet provides lots of information, some of it is accurate and helpful and some inaccurate and anything but helpful. However, many world-class cancer centres provide information online 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.

## WHAT CAN I DO?

Established in 2009 by two bladder cancer survivors, Bladder Cancer Canada was the first Canadian patient advocacy organization dedicated to bladder cancer issues. BCC is a national registered charity and the only one devoted to bladder cancer patients and survivors and the caregivers who support them. BCC does not receive any government funding and relies on donations to offer programs and services, such as this free guidebook, to patients and their families.

### Support us

Individual donations are greatly appreciated, and tax receipts are issued for donations of \$20 or more. Donations can be made online at [bladdercancercanada.org](http://bladdercancercanada.org) or by calling 1-866-674-8889. Your support will help BCC to continue and expand our programs and services to help even more patients and caregivers like you.

**Thank you.**

### Walk with us

Each September, Bladder Cancer Canada holds awareness walks in numerous cities across Canada. The walks are one of the main sources of funding for Bladder Cancer Canada and raise approximately two-thirds of our funds for the entire year for patient support programs, awareness initiatives, and bladder cancer research. A walk in the park is not a cure, but it’s a good start. Join us at **BCCwalk.ca**

### Spread the word

Tell your friends, family and healthcare providers about bladder cancer and Bladder Cancer Canada. You can speak with others on the same journey and 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](http://www.bladdercancercanada.org). Our website has excellent, reliable, and active discussion forums where you can ask questions or share your story. You can also sign up for our e-newsletter to stay up-to-date on upcoming events and 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>
- **Mayo Clinic**  
<https://www.mayoclinic.org/diseases-conditions/bladder-cancer/symptoms-causes/syc-20356104>
- **Cleveland Clinic**  
<http://my.clevelandclinic.org/urology-kidney/diseases-conditions/bladder-cancer.aspx>
- **Johns Hopkins**  
<http://urology.jhu.edu/bladder/>
- **Bladder Cancer Advocacy Network (BCAN US)** - <http://www.bcan.org/>
- **Canadian Cancer Society**  
<http://www.cancer.ca/en/cancer-information/cancer-type/bladder/bladder-cancer/>
- **Canadian Urological Association**  
<http://www.cua.org/>
- **National Cancer Institute (US)**  
<http://www.cancer.gov/cancertopics/types/bladder>
- **Cornell Urology**  
<https://urology.weillcornell.org/bladder-cancer>

# ABOUT BLADDER CANCER CANADA (BCC)

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](http://www.bladdercancerCanada.org).

## CONTACT US

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## SPECIAL THANK YOU NOTES

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[bladdercancerCanada.org](http://bladdercancerCanada.org)  
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