BLADDER CANCER
PATIENT GUIDEBOOK
FOR PATIENTS WITH NONMUSCLE-INVASIVE BLADDER CANCER
YOU ARE NOT ALONE

This guidebook was created by people just like you – bladder cancer patients and their caregivers. It is 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.

This guidebook will talk about common approaches to treating nonmuscle-invasive bladder cancer (NMIBC), but 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/en/facing-bladder-cancer/glossary-of-terms.

Remember, you are 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.

From vision to reality: 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.

Many sections of this guidebook are based on his original writing and we are grateful for his inspiration.

The strength of Greg’s commitment to helping fellow bladder cancer patients and caregivers reaches far beyond this guidebook. A frequent contributor on Bladder Cancer Canada’s web forums, Greg offers information, guidance, support and encouragement with compassion and a superb sense of humour. He has inspired and brought comfort to many through his talks at patient meetings. Greg has written many articles for Bladder Cancer Canada and for outside publications, has chaired our Awareness Walk in Toronto and has been a positive presence at medical and patient meetings.

Thank you, Greg, for your dedication to those fighting bladder cancer and to Bladder Cancer Canada.
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. You’re one of about 80,000 Canadians who have the disease and about 8,000 more are diagnosed every year.

Approximately 75% of bladder cancers are 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. If you smoke, you 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 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.”

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. See the panel to the right for a description of each stage.

IMPORTANT

Keep a copy of the pathology report which will tell you the stage and grade of your tumour. The grade, along with the stage, will be used to determine the proper treatment for you.
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 and may be asked to spend time lying down and 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.

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 http://www.cancer.org/cancer/bladdercancer/detailedguide/bladder-cancer-new-research.

PATIENT TRIALS

Occasionally, researchers conduct trials for new treatments and therapies. Talk to your urologist about any trials that may be available to you and whether your urologist feels it would be worthwhile.

When thinking about participating in a trial, consider whether the treatment or therapy being studied may have better potential to help you than the standard treatment you’re receiving. Clinical trials need participants and would naturally like to recruit you, if you qualify – just make sure it’s in your best interest.
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.

After “all clear” examinations for two years, cystoscopies should be repeated every six months for two years and then annually for the rest of your life. It is not uncommon for patients to go several years without any recurrence, only to find that a tumour has formed the following year!

NEVER NEGLECT A FOLLOW-UP APPOINTMENT

The prognosis is very good for you to live a long, healthy life. Be encouraged. Be diligent. And choose to help someone else who faces this diagnosis to look ahead with a positive attitude. Check the inside back cover of this guidebook for ways you can help.
WHERE ELSE CAN I GET INFORMATION?

The Bladder Cancer Canada website (www.bladdercancercanada.org) has a wealth of information, including a Patient Guidebook for Muscle-Invasive Bladder Cancer. The New Normal Guidebook explores ways you can change your lifestyle that are helpful in living with bladder cancer.

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. These 5 km walks allow us to tell Canadians about this common cancer. The walks also enable us to raise much-needed funds to 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.

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.

Patient education meetings are held in cities across Canada each year. We would love to see you there. These also need local volunteers to coordinate.

To find out how you can help – or to 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.

HELPFUL WEBSITES:

- Bladder Cancer Canada https://www.bladdercancercanada.org
- Mayo Clinic - http://www.mayoclinic.org/diseases-conditions/bladder-cancer/basics/definition/con-20027606
- Johns Hopkins http://urology.jhu.edu/bladder/
- Bladder Cancer Advocacy Network (BCAN US) - http://www.bcan.org/
- Canadian Urological Association http://www.cua.org/
- National Cancer Institute (US) http://www.cancer.gov/cancertopics/types/bladder

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!
ABOUT BLADDER CANCER CANADA (BCC)

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 our website at www.bladdercancercanada.org, email us at info@bladdercancercanada.org or call us at 1-866-674-8889.

A special thank you

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