

**BLADDER
CANCER**

CAREGIVERS GUIDEBOOK

**FOR THOSE PROVIDING SUPPORT
FOR BLADDER CANCER PATIENTS**



**BLADDER
CANCER
CANADA**



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To ensure accuracy, this Guidebook has been reviewed by a team of medical professionals.

YOU ARE NOT ALONE



This Guidebook was created by people just like you – people who are providing care to bladder cancer patients. Your role is an important one and can have a positive impact on your friend or family member throughout the stages of their diagnosis, treatment and recovery.

There are three main roles for the caregiver that we'll discuss throughout this Guidebook:

- 1.** You'll help the patient **understand information** about the disease, how it is being diagnosed, how it will be treated and what needs to be done during recovery.
- 2.** You'll provide **physical or practical support**, such as helping with self-care and assisting with daily tasks at home when the patient needs help.
- 3.** You'll offer **emotional support**. This can be especially important for cancer patients experiencing the difficult emotions a cancer diagnosis can generate.

The caregiver role can be challenging as well as rewarding. The role will transition a number of times during the course of the patient's disease. This Guidebook will help you understand your role during these stages of the disease:

- Prior to treatment (during diagnosis and, perhaps even when symptoms first arise)
- During treatment
- After treatment (during recovery)

We'll also offer some tips on how to take care of yourself when you feel overwhelmed and tired.

PRIOR TO TREATMENT

IDENTIFYING SYMPTOMS

Depending on your relationship, you may be in a position to help someone identify the symptoms of bladder cancer and urge them to see their doctor.

Here are some of the most common signs of bladder cancer:

- Blood or blood clots in the urine
- Pain or burning sensation when urinating
- Frequent urination, especially at night
- The urge to urinate, even when the bladder isn't full
- Lower back pain on one side

In addition, bladder cancer that has spread to other parts of the body may include:

- Weight loss and loss of appetite
- Fatigue, weakness and general discomfort
- Swelling in the feet
- Bone pain
- Swollen lymph nodes
- Shortness of breath or coughing

It's important to note that people may not have all these signs and symptoms. Also, some of the symptoms listed above may be signs of other conditions. The symptoms are also dependent on which part of body the cancer has spread to.

How you can help

If the person you are close to experiences any of these symptoms, urge them to see their family doctor immediately. Many bladder cancers can be successfully treated if detected early.

Sometimes, a family doctor may suspect a urinary tract infection is causing some of the early symptoms listed above. In many cases, that may be true. However, the patient can always seek a second opinion to be safe, especially if they have any of the symptoms listed above, if there is a history of bladder cancer in the family or if the patient has high-risk habits, such as smoking.

HOW IS BLADDER CANCER DIAGNOSED?

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 tests – 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) into the bladder to examine the lining of the bladder for tumors. It can be done in a doctor's office or in a hospital setting with local anesthesia.

Transurethral resection of bladder tumor (TURBT) – A surgical procedure done under general or spinal anesthesia in a hospital setting, to biopsy any abnormal tissue found during a cystoscopy. Note that there is no abdominal incision with a TURBT.

Scans – Help detect if the cancer has spread and they help to determine what stage the cancer has progressed to. Types of scans that may be used include "Computed tomography" (CT or CAT) scan, "Magnetic resonance imaging" (MRI), and "Positron emission tomography" (PET or PET-CT).

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

How you can help

Most of the tests can be done without a caregiver accompanying the patient. However, it can be helpful if you understand the tests when supporting the patient.

For TURBT:

- Since anesthesia is required, the patient is not allowed to drive immediately afterwards. A caregiver is required for transportation. If allowed by the facility, the patient might benefit from having a caregiver present to offer comfort after the procedure.

- When discharged, make sure post-operative care instructions outline what to expect during recovery and who to contact if there are any concerns, especially if there are symptoms of infection. Check to see if a prescription is required for pain or an antibiotic to prevent infection. Difficulty urinating after the patient gets home can be a life-threatening situation and must be treated at an emergency room immediately.
- Caregivers may need to discuss with the medical team when the patient can drive, have sex, return to work or any other limitations after the TURBT.

After diagnostic tests are complete, the doctor will review all results with the patient. If the diagnosis is cancer, these results also help the doctor describe the cancer. This is called staging and grading.

How you can help

- Caregivers can provide emotional support and help the patient understand the details of the cancer diagnosis. Consider starting a journal to record information and communicate questions and concerns both you and the patient would like answered at appointments and throughout the cancer journey.
- As a caregiver, it would be very helpful to accompany the patient to the appointment with the doctor. It can be difficult to absorb all the information about the diagnosis, especially when feeling stressed. You can help by taking notes and ensuring that all the patient's questions (and yours!) are answered.
- Ensure the patient keeps a copy of the pathology report, which will confirm the diagnosis and the grade of the tumour. Bear in mind that the pathology report will not reveal where else the cancer is or may be.

THIS IS WHEN EMOTIONAL SUPPORT IS NEEDED MOST

A diagnosis of any type of cancer can be devastating – for both the patient and you, as a caregiver. Shock is often the first reaction, followed by anger, sadness, denial and fear. It can be hard to watch someone you care about going through these emotions.

How you can help

First, listen to the patient without judging. Resist the temptation to say: “I’m so sorry” (which can increase the patient’s negative emotions) or “Don’t worry, everything’s going to be all right” (which can offer false hope). Let the patient know that you are – and will be – there for them, physically and emotionally. Treatment can be a long haul and no one wants to face it alone.

Never hesitate to be a strong advocate for the patient if you instinctively feel something needs to be addressed or has been missed! Always ask about potential complications, how to recognize them and, if possible, how to prevent them. Request all available literature for review.

TREATMENT OPTIONS

Depending on the diagnosis, there can be a number of treatment options. The patient’s doctor, or a team of specialists, will discuss what treatments are available. Sometimes there will be options for treatment that the patient will need to decide on in consultation with their family doctor.

The treatment options can include:

- **Surgically removing the bladder (called a radical cystectomy) and:**
 - Using a section of bowel to create a type of replacement bladder called a neobladder to collect urine
 - Diverting the urine into an external collection bag
 - Using a section of bowel to create an internal pouch to collect the urine
 - Chemotherapy (pre- or post-surgery or radiation), immunotherapy and/or radiation
- **Non-surgical treatments for non-muscle-invasive bladder cancer**
- **Preserving the bladder or removing only the cancerous part of the bladder**

Please refer to the Patient Guidebook series available free of charge from Bladder Cancer Canada for details on the various treatments. There are separate Guidebooks for each major type of bladder cancer. Be sure to ask the specialist team about which treatment for the patient’s particular diagnosis has proven to have a better outcome; for example, therapy treatments followed by surgery, or surgery followed by treatment.

How you can help

The Guidebooks are a valuable resource to help you and the patient you are supporting to understand the treatments available. Help the patient by ordering or downloading the appropriate Guidebook from Bladder Cancer Canada's website and encouraging them to read through it to understand what's ahead.

Some general ways you can help throughout the process include:

- Accompanying the patient to appointments for emotional support and take notes, as it is sometimes difficult to remember all the details the medical team is providing.
- Recording any questions for the medical team and help the patient communicate with the medical team. Maintaining a journal or notebook can be helpful.



The following sections discuss the main caregiver role in each of the major treatments for bladder cancer. It's helpful to have a copy of the Guidebook for the appropriate treatment in front of you when working through the ways in which you can support the patient undergoing treatment.

RADICAL CYSTECTOMY

The majority of patients with muscle-invasive bladder cancer will be treated with radical cystectomy - major surgery to remove the diseased bladder and to construct a new urinary diversion. There are three types of urinary diversion:

- **Ileal conduit (ostomy)**
- **Orthotopic neobladder**
- **Indiana pouch**

For more information, please refer to the Guidebook for Patients Facing Radical Cystectomy.

How you can help

The patient will come home from the hospital tired, will have reduced energy and loss of appetite. Here are some tips for you as a caregiver:

- To help the patient rest, help them to get into a comfortable position. This may mean adjusting any drainage tubes and urine collection bags the patient came home with from the hospital.
- The patient will need to avoid lifting until the surgery heals, so make sure items the patient may need are within easy reach.
- You will need to ensure that the patient has a soft diet. Your medical team will advise you on what typed of foods the patient can eat and for how long after surgery.
- The patient has had major surgery and may be "emotionally down." You can play an important role in keeping the patient's spirits up. It is definitely a factor in a good recovery.

With a neobladder:

- The patient will come home from the hospital with a number of drainage tubes and urine collection bags. The tubes will need to be flushed to drain excess mucus on a schedule recommended by the medical team. You can help ensure that the syringe used and the open ends of the tubes are carefully disinfected with alcohol before each use. This will help avoid infections. You should also help the patient track the time between flushings.
- After the tubes are out, the patient will need to empty the neobladder frequently, on a schedule recommended by the medical team. Again, you can help time the urinations.
- There could be some incontinence, particularly at night. Continence tends to gradually return, although catheterization may be required in some cases. As caregiver, you can help by ensuring the patient wears an absorbent pad in situations where a washroom is not close by. The patient may also need to wear incontinence underwear, especially at night, and sleep on mattress protection. It helps if the patient gets up several times during the night to urinate. Again, you can help with timing.

With an Ileal conduit:

- The patient will have an opening in the abdomen called a “stoma.” The stoma will need to be kept very clean and moisturized to avoid the breakdown of skin around the stoma and infections. The patient will be taught will to do this and how to attach the urine collection bag. You can attend the training with the patient so you can help, especially if the patient is not yet comfortable with the process or has difficulty applying the stoma attachment and bag.
- You can help the patient to research the types of bags and stoma attachments that are available.

With an Indiana pouch:

- Similar to an ileal conduit, the patient with an Indiana pouch will have a stoma through which a catheter is inserted to drain urine from the pouch.
- The stoma will need to be kept very clean and moisturized to avoid the breakdown of skin around the stoma and infections. The patient will be taught will to do this and how use the catheter. You can attend the training with the patient so you can help, especially if the patient is not yet comfortable with the process or has difficulty inserting the catheter.

With all radical cystectomies:

- In men, there may well be erectile dysfunction and, in women, intimacy may be painful. The patient and you should discuss any treatments with the medical team. As the patient’s partner, it helps if you are understanding, patient and supportive.

NON-MUSCLE-INVASIVE BLADDER CANCER

Bladder cancer that has not spread into the muscle is typically treated with drugs, such as BCG (Bacillus Calmette-Guérin), Mitomycin C, a combination of Gemcitabine and Docetaxel, and EMDA (Electromotive Drug Administration). Refer to the Non-muscle-Invasive Bladder Cancer Guidebook for details on how these drugs are administered.

How you can help

- These treatments involve a number of trips to the hospital and may need someone to do the driving. You can reinforce the need to follow through with the complete course of treatment to maximize the effectiveness.
- You should also watch for any side effects, which tend to be cumulative, and make sure the medical team is alerted. In some cases, dosages can be adjusted or breaks between treatments can be extended to reduce side effects.

BLADDER PRESERVATION

In some cases, selected patients can qualify for treatment that preserves the bladder. This involves a combination of three treatments: a TURBT (Transurethral resection of bladder tumor), followed by chemotherapy and then a combination of radiation and chemotherapy. Refer to the Bladder Preservation Guidebook for more details.

How you can help

- These treatments involve a number of trips to the hospital and may need someone to do the driving, especially with the TURBT which is done under general anesthetic. You can reinforce the need to follow through with the complete course of treatment to maximize the effectiveness.
- You should also watch for any side effects and make sure the medical team is alerted, as there are treatments that be used to reduce the side effects. Side effects can occur four to six weeks after treatment.
- If the doctor recommends bladder removal, the patient can ask for a second opinion, as bladder preservation can be as effective as bladder removal in specific cases.



TAKING CARE OF YOURSELF

Being a caregiver to someone with bladder cancer can be tiring physically and emotionally. The patient is depending on you for support, but you can only be effective if you also take care of yourself.

Here are some ways that you can avoid “caregiver burnout”:

- Make sure you get enough sleep, eat a balanced diet and get regular exercise.
- Set aside time for yourself and maintain the hobbies and pastimes that give you enjoyment.
- You can't do everything, especially if you have work outside the home. You may need to find help with cooking, laundry, transportation and other chores.
- Make sure you take care of your own medical needs.

Bladder cancer is generally very treatable, especially if caught early. However, as with any serious disease, death is possible. Make sure you have end-of-life discussions with the patient. You may need to engage a lawyer to ensure that a will and health directive are prepared.

FIND SUPPORT FOR YOURSELF

There are also support groups for bladder cancer and/or caregiving. Bladder Cancer Canada has a number of support groups, including one specifically for caregivers. Contact us to learn more about support groups in your area or educational webinars. Also, visit the Canadian Centre for Caregiving Excellence website to find out about the caregiving organizations and resources available in your province.

GET INVOLVED

As the first and only Canadian patient advocacy organization dedicated to bladder cancer issues, Bladder Cancer Canada is proud to provide patients, their caregivers and families with the support and resources to help navigate a bladder cancer diagnosis. Bladder Cancer Canada 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 can be made online at bladdercancer.ca or by calling 1-866-674-8889. Your support will help Bladder Cancer Canada to continue and expand our programs and services to help even more patients and caregivers.

WALK WITH US

Each September, we host our annual walk, **Canada Walks for Bladder Cancer**, in cities across the country. This event plays a vital role in our mission to increase awareness of bladder cancer in communities across Canada, provide support to bladder cancer patients and fund innovative research. The money generated from this event makes up around two-thirds of our annual income. Help create a world where bladder cancer is just a memory. **Join us at BCCwalk.ca**

VOLUNTEER & 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.bladdercancer.ca. Our website has excellent, reliable, and active discussion forums where you can ask questions or share your story. You can also find information on volunteering or 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.

Contact us today – We are here to help.

ABOUT BLADDER CANCER CANADA

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 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 is working to change this.

For more information, visit bladdercancerCanada.org


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