# BLADDER CANCER PATIENT GUIDEBOOK



FOR PATIENTS FACING RADICAL CYSTECTOMY



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# 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 muscle-invasive bladder cancer (MIBC), 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.

# 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."

## MUSCLE-INVASIVE BLADDER CANCER

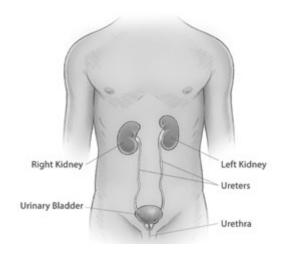
Many of us never knew bladder cancer existed before our diagnosis. But, it's more common than you might think, as it's the 5th most common cancer in Canada. You're one of about 80,000 Canadians who have the disease and about 8,000 more are diagnosed every year.

Approximately 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 (radical cystectomy) and create a new path for urine to leave the body. We'll explore the treatments in more depth as we go along.

# UNDERSTANDING HOW THE BODY WORKS

Radical cystectomy is a big operation involving two body systems - the urinary and the intestinal systems. The more we understand about how the two systems work, the better our recovery will be. Here's a brief description of these two vital systems.

### THE URINARY SYSTEM



The body takes nutrients from food and changes the nutrients to energy. After the body takes the nutrition that it needs, waste products are left behind in the blood and in the bowel.

The urinary system removes the waste product called urea from the blood. Urea is made when foods containing protein (meats and some vegetables) are broken down in the body and carried in the blood to the kidneys.

### Our two kidneys:

- Remove liquid waste from the blood in the form of urine
- Balance salts and other substances in the blood
- Help regulate blood pressure
- Make erythropoietin, a hormone that helps make red blood cells

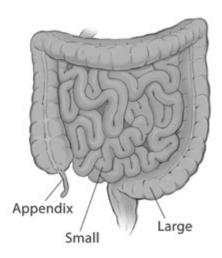
### Parts of the urinary system:

The kidneys remove urea from the blood through tiny filtering units called nephrons. Urea, water and other waste substances make the urine as they pass through the nephrons and down the renal tubules of the kidney.

 The two ureters are narrow tubes that carry urine from the kidneys to the bladder. Muscles in the ureter walls continually tighten and relax forcing urine downward, away from the kidneys. If urine backs up, or is allowed to stand still, it can lead to kidney infection, damage, or failure. About every 10 to 15 seconds, small amounts of urine are emptied into the bladder from the ureters.

- The bladder is a triangle-shaped, hollow organ located in the lower abdomen. It is held in place by ligaments that are attached to other organs and the pelvic bones. The bladder's muscle walls relax and expand to store urine, and contract and flatten to empty urine through the urethra.
- Two, circular sphincter muscles help keep urine from leaking out of the body by closing tightly like a rubber band around the opening of the bladder.
- Nerves in the bladder alert a person when it is time to urinate, or empty the bladder.
- The urethra is the tube that allows urine to pass outside the body. The brain signals the bladder muscles to tighten, which squeeze urine out of the bladder. At the same time, the brain signals the sphincter muscles to relax to let urine exit the bladder through the urethra. When all the signals occur in the correct order, normal urination occurs.

### THE INTESTINAL SYSTEM



The intestines are a long, continuous tube running from the stomach to the opening where the stool leaves the body (anus). Most absorption of nutrients and water happen in the intestines, which include the small intestine, large intestine, and rectum.

The small intestine (small bowel) is about 20 feet long and about an inch in diameter. Its job is to absorb most of the nutrients from what we eat and drink. Velvety tissue lines the small intestine, which is divided into the duodenum, jejunum, and ileum.

The large intestine (colon or large bowel) is about 5 feet long and about 3 inches in diameter, and creates formed stool, once the nutrients are absorbed. As stool enters the rectum, nerves there create the urge to have a bowel movement.

# STAGING AND GRADING YOUR BLADDER CANCER

Laboratory analysis of the material taken out during your 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 page five 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.

## HOW WILL MY CANCER BE TREATED?

Although in selected patients, treatments to preserve the bladder (such as combined chemotherapy plus radiation) may be an option, 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.

In men, the surgeon will remove the bladder, prostate, seminal vesicles and pelvic lymph nodes, usually a dozen or more. In women, the surgeon may remove not only the bladder, but also the uterus, ovaries, fallopian tubes, cervix, front wall of the vagina and pelvic lymph nodes.

For both men and women, the surgeon may also remove the urethra, depending on which diversion is to be created.

### QUESTIONS TO ASK YOUR SURGEON

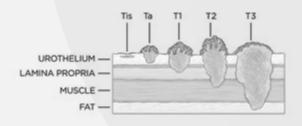
- Do you construct neobladders and Indiana Pouches as well as ileal conduits? (You will find information about these beginning on the next page)
- Will I need chemotherapy?
- What kind of follow-up will I require from you?
- What limitations will this surgery impose on my life (physical, emotional, sexual)?
- What are the common complications of surgery and longterm effects of the disease?
- Are there any patients of yours with whom I can speak who have had this surgery?
- Am I able to obtain a second opinion from a major cancer/ teaching centre?

When you meet with your surgeon, take a family member or close friend with you to take notes and to be a listening ear. You'll miss some of the information if you are by yourself.

Write down questions you want the surgeon to answer before you get there so that you don't forget them. You could even ask permission to record the interview so that you can replay the questions and answers when you get home.

# THE BLADDER IS GONE - NOW WHAT?

Once the bladder is removed, your surgeon needs to create a new way for the urine to drain from the kidneys to outside the body. The options are called "diversions." In Canada, three diversions are common – ileal conduit, orthotopic neobladder and Indiana Pouch. You will want to discuss these with your surgeon to understand which is appropriate for you and why.



### **STAGING**

Tis - Carcinoma in situ (flat tumour)

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).

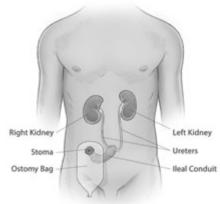
Nonmuscle-invasive means that the tumour has not invaded the muscle of the bladder (muscularis propria). It has grown into the layer of cells that line the bladder (transitional epithelium) and perhaps into the connective tissue below (lamina propria). The early stages of nonmuscle-invasive bladder cancer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

#### **GRADING**

The pathology report 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.

### **ILEAL CONDUIT (OSTOMY)**

The surgeon will take a short segment of the ileum (part of the small intestine) to create a channel for the urine to pass out of the body. The remaining bowel is sewn back together. The two ureters from the kidneys which drain the urine are attached to this segment and an opening in the right side of the abdomen is created, called a stoma. A removable bag, called a urostomy pouch, is affixed to the skin surrounding the stoma to catch the continuous flow of urine.

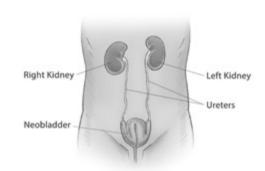


**Advantages:** Shorter and relatively simple surgery, fewer potential complications, shorter segment of bowel re-purposed.

**Disadvantages:** Must always wear an external pouch to collect urine, possible skin irritation/breakdown around stoma, infections, body image issues, potential for odour, potential for leaks.

### ORTHOTOPIC NEOBLADDER

The surgeon will create a "new" bladder out of a longer segment of small intestine in the same place as the old, diseased bladder was. This neobladder will be attached to the ureters from the kidneys and also attached to the urethra so that voiding urine is done as before.



The neobladder is not a muscle like your original bladder was, and does not have the same "fullness" sensations as does a bladder, so you must learn how to "hold" your urine (become continent) and how to effectively empty it using the pelvic muscles.

**Advantages**: Near normal function, no body image issues, no external pouches, no odours.

**Disadvantages**: Incontinence (as some may never regain full control), the inability to empty the neobladder (some may need to use a catheter daily to empty the neobladder), longer surgery time, potential for restricted flow.

### **INDIANA POUCH**



The surgeon will take a segment of large intestine and a small portion of the ileum to make an internal pouch into which the ureters flow. The short piece of small intestine is brought to the surface of the abdomen (the stoma). There is no external pouch and the stoma is very small, and can be covered with a bandage.

A catheter inserted into the stoma is used several times per day to empty the pouch.

**Advantages:** No external pouch, no odours, no body image issues.

**Disadvantages:** Longer surgery time, the need for catheterization, possible risk of leakage from the stoma, scarring of the stoma making catherization difficult, stones in the pouch.

# COMMON ISSUES FOLLOWING RADICAL CYSTECTOMY SURGERY

Radical cystectomy and creating a urinary diversion is major abdominal surgery. As with all major surgeries, some issues are bound to arise. Some of them gradually disappear and others you adapt to over time.

- 1. Temporary loss of appetite
- 2. Reduced energy
- 3. Fatigue
- 4. Loss of weight
- 5. Infections
- 6. Erectile dysfunction in men (you need to discuss potential treatments for this with your surgeon)
- 7. Painful intimacy in women
- 8. Body image issues
- 9. Anxiety
- 10. Feeling "different"
- Mucus in urine (which is continually produced by the intestinal section used to make the diversion) is unsightly and can potentially cause blockage and the need for catheterization

### **CHEMOTHERAPY**

Before removing the bladder, chemotherapy is often recommended (called neoadjuvant chemotherapy). The purpose of the treatment prior to surgery is to stop the disease from spreading through the blood or lymph system to other parts of the body and to reduce the tumours. In addition, chemotherapy is usually better tolerated prior to major surgery.

Not everyone is a candidate for pre-operative chemotherapy, however, and in such cases, it may be advisable to have post-surgery chemotherapy (called adjuvant chemotherapy). If lymph nodes are affected by the cancer, the oncologist may recommend adjuvant chemotherapy to combat further spread. The risk is that patients may decline post-surgery chemotherapy. This can happen for a number of reasons, including the fear of side effects, weakness and fatigue from the surgery itself, or thinking that the cancer is gone so chemotherapy is not necessary.

Chemotherapy has side effects which can be unpleasant and these must be taken into account by both you and your doctor. However, since the goal is to extend life with good quality, you should make an informed decision, based on the recommendation of your doctor.

Do not hesitate to call Bladder Cancer Canada and ask to speak with someone who has had the surgery you are preparing to receive. We have many peer support volunteers who will answer any questions you have based on their own experience and acquired knowledge. It is a big help to chat with someone who has been in your shoes – and is surviving and thriving. We know. We have been there!

### PREPARING FOR THE SURGERY

### WHAT TO BRING TO THE HOSPITAL

- Slip-on shoes or slippers you'll be walking a lot
- Some books to read
- Tear-away sports pants to use when you tire of the hospital gown
- A list of all your medications
- You should not bring valuables into the hospital that may be lost or stolen

### WHAT TO EXPECT AFTER YOUR SURGERY

As you can see, radical cystectomy is very major surgery and you'll have a lengthy recovery. Many parts of the body are affected during the surgery and need time to heal.

On average, your hospital stay will be 5 to 10 days. Walking starts the day after surgery. This helps the bowels to start working again. Remember, this is bowel surgery too, not just bladder surgery! Expect to be on a liquid diet for the first few days before solid foods are gradually introduced.

While in hospital, you'll have a number of IV lines and tubes, depending on your type of surgery. These will provide pain control, urine drainage and drainage of excess fluid from the surgical site.

### **RETURNING HOME AFTER SURGERY**

It's not unusual for your weight to change during your hospital stay and first few weeks at home. There will be some muscle and fat weight loss, but there could be some weight gain through fluid retention. The excess fluid will gradually be cleared by the kidneys.

You've had major surgery, so your recovery will be gradual. Keep a record of your progress - how many and what length of walks you've taken (even walks in the hallways of your home count).

You may also need soft, small icepacks (your groin area will be swollen for a while, which is a normal part of healing). In men, the scrotum, which contains the testicles, may swell considerably.

It's important to keep the incision clean and dry until it heals. Home care is usually ordered to check on dressings and change them and to remove the stitches or staples. If you have any issues, call the surgeon's office or urologist on call. If you develop a fever, go to the nearest Emergency Room as soon as possible (it may be an indication of infection).

### **EATING AND NUTRITION**

You'll need to eat small, frequent meals, which are easier on the healing bowels and shrunken stomach. You must drink at least 64 ounces of water (eight 8-ounce glasses of water or other liquids) per day. This is necessary to keep the kidneys clear, keep mucus thinner and easier to pass and not block up anywhere, and keep stools softer and easier to pass.

Mucus will continue to be produced by the parts of the intestines that were used for the diversion, probably forever. So, drinking lots of water will become a lifetime commitment.

Soups and stews are easy to digest, easier on the healing bowels and the easiest way to keep high nutrition for healing (try grating vegetables into soups or stews). For the first weeks, avoid fats and high-fibre foods, like popcorn and raw or undercooked vegetables.

### **BOWEL CARE**

You'll need to keep your stool soft as the bowel heals. Daily stool softeners may be recommended by your surgeon (they're available over the counter at drug stores). You'll want to limit straining while having a bowel movement to help the bowel heal, avoid putting a strain on the stitches or staples and reduce the risk of haemorrhoids.

If you are constipated, some fibre intake may help, but it also means drinking plenty of water, as the fibre needs lots of water to work as a softener (the fibre can cause constipation if you don't drink enough water).

There are cases where a blockage can occur in the bowel, often at the point where the sections of the bowel were re-joined during surgery. Walking a lot will help and sometimes chewing gum is recommended.

### **EXERCISE**

The bowels need gentle physical activity to start working again. Walking is the best form of exercise for the first six weeks to three months - the body's healing time.

### **EMOTIONS**

Your emotions can best be described as "a rollercoaster." That's perfectly normal – after all, you've been diagnosed with cancer, you've had major abdominal surgery, and you're faced with a new lifestyle. 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.

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

# AT HOME WITH YOUR ILEAL CONDUIT (OSTOMY)

The first week after your surgery your stoma may be tender and may be dark or bruised, swollen or blister-like or have spongy or yellow tissue around it. This tissue will peel off in a few days and start to look more normal. You'll also notice stitches attaching it to your skin. These will be absorbed on their own and the swelling should go down in three or four weeks.

A normal healthy stoma looks soft, moist, red or pink and shiny. The skin around your stoma should look like the rest of the skin on your abdomen. It should be free of rashes, redness, scratches and bruising. If the stoma becomes irritated, get in touch with your stoma nurse, as there are products to help.

Your nurses in the hospital or home care will teach you how to empty, clean and change your new urine collection pouch and how to set up a night collection system.

Once your stoma size has stabilized, you'll determine the correct size for your urostomy bag, using the stoma measuring devices supplied by the ET nurse and the ostomy supply companies in their sample kits.

If your stoma is round, experienced patients recommend using an external bag with an opening pre-cut to size. This avoids trying to precision cut a round hole – not easy and certainly not fun! Many of us find that a one-piece appliance (another name for the urostomy bag, also called a pouch) is easier to handle than a two-piece unit with a flange and then adding the bag, which is much bulkier. But try them both.

Another tip - for men, suspenders are a lot easier on the appliance and the area around the stoma than a belt.

Again, this is something that you will try and work with and find what combination best works for you.

Supplies are available at home healthcare or other medical supply stores. Experiment with different ostomy products and contact the providers as they have patient support personnel who can help. Major suppliers include Hollister (www.hollister.com/canada/ostomy/) and Coloplast (www.coloplast.ca/Ostomy/). Both companies offer free samples of their products.

For additional information and tips, read "The New Normal - Living with your Ileal Conduit (Ostomy)," available on Bladder Cancer Canada's website www.bladdercancercanada.org.

## AT HOME WITH YOUR NEOBLADDER

Neobladder patients are typically sent home with two tubes – a catheter in the urethra and a "suprapubic" catheter in the abdomen, both helping drain the new neobladder. Your nurses in the hospital or home care will teach you how to "flush" the tubes to clear mucus.

This flushing needs to be done at regular intervals, as recommended by your medical team, usually about every four hours day and night. It doesn't hurt to flush more frequently. You should seek immediate medical attention if you are unable to flush the mucus and urine through the tubes – there may be a blockage.

Since you will be sleeping with urine collection bags attached to tubes, experiment until you find a comfortable sleeping position. You may need something to sleep in other than pyjamas, because of the restrictions of the tubes.

After the tubes are removed in a few weeks, it's normal to have incontinence and you may need to wear disposable underwear or pads. Daytime continence usually returns, but night time incontinence can be a lifetime issue. Lots of patience is essential. Washable bed protectors (available at home healthcare or medical supply stores) are necessary.

For additional information and tips, read "The New Normal - Living with your Neobladder," available on Bladder Cancer Canada's website www.bladdercancercanada.org.

# AT HOME WITH YOUR INDIANA POUCH

The first week after your surgery your stoma may look dark or bruised, look swollen or blister-like or have spongy or yellow tissue around it. This tissue will peel off in a few days and start to look more normal.

A normal healthy stoma looks soft, moist, red or pink and shiny and should be flush with the skin. The skin around your stoma should look like the rest of the skin on your abdomen. It should be free of rashes, redness, scratches and bruising.

Typically, patients are sent home with a "suprapubic" catheter in the abdomen and possibly a small tube in the new stoma, both helping drain the pouch of urine and mucus for several weeks. Your nurses in the hospital or home care will teach you how to "flush" the tubes to while you're still in hospital. This flushing needs to be done at regular intervals, as recommended by your medical team.

Your nurses in the hospital or homecare will also teach you how to take care of your stoma and catheterize your new Indiana Pouch, once the tubes are taken out. Usually, you will begin by catheterizing every two hours for the first week or so, gradually increasing the time between catheterizations as the pouch begins to stretch. Catheters are available at home healthcare or other medical supply stores.

For additional information and tips, read "The New Normal - Living with your Indiana Pouch," available on Bladder Cancer Canada's website www.bladdercancercanada.org.

### A LIFETIME OF CHECKUPS

Of course, it's a great relief to hear your doctor say the words "all clear" after your first checkup. However that's not the end of this chapter of your life. You'll need regular checkups, usually including CT scans and blood work. These checkups will be more frequent at first and gradually reduced to one or two a year for the rest of your life 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. The New Normal Guidebooks explore ways you can change your lifestyle that are helpful in living with bladder cancer.

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 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.



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!

### **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 the 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
- 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://www.cornellurology.com/ clinical-conditions/bladder-cancer/



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

### A special thank you

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