

**BLADDER  
CANCER**

# **PATIENT GUIDEBOOK**

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**FOR PATIENTS WITH  
UPPER TRACT UROTHELIAL  
CARCINOMA**



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## YOU ARE NOT ALONE



This Patient Guidebook was created by people just like you - upper tract urothelial carcinoma 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 disease. It can help you understand your disease, what to expect, the treatments you may be offered and how to manage your disease and its side effects.

We're 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 upper tract urothelial carcinoma. Keep in mind that there can be some differences, depending on the practices of your medical team and on your specific situation. We'll 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 upper tract urothelial carcinoma. We're doing it and so can you.**

## WHAT IS UPPER TRACT UROTHELIAL CARCINOMA?

As opposed to urothelial carcinoma of the bladder (lower urinary tract cancer), upper tract urothelial carcinoma (also called “upper urinary tract cancer”) is a cancer in the lining of the upper urinary system. This can occur in three places:

- The inner lining of the kidney
- The spaces in the kidneys
- The tubes that connect the kidneys to the bladder (called the “ureters”)

Upper tract urothelial carcinoma (UTUC) represents approximately 5% to 10% of cancers of the urinary system (the rest occur in the bladder). The most common UTUCs are found in the lining of the kidney. Cancer in the ureters makes up about 25% of UTUCs.

UTUCs start in the inner lining of the kidney and ureters (called the “urothelium”). Cancer that starts in the urothelium is called “urothelial carcinoma.” An older name for this is also “transitional cell carcinoma.”

## WHAT CAUSES UPPER TRACT UROTHELIAL CARCINOMA?

It’s not known exactly what causes UTUC, but there are some risk factors and associations:

- Smoking
- History of bladder cancer
- Men are 2x more affected than females
- Less common among African-Canadians than among Caucasians
- More common over age 70 and seldom in patients less than 40 years
- Chemical exposure during production of plastics, textiles, leather and rubber
- Long-term use of the painkiller phenacetin (withdrawn from Canadian market in 1973)
- Use of certain herbs used for weight loss (aristolochic acid)
- Family history, including specific genetic syndromes in a small number of patients (e.g., Lynch syndrome)

## SIGNS AND SYMPTOMS

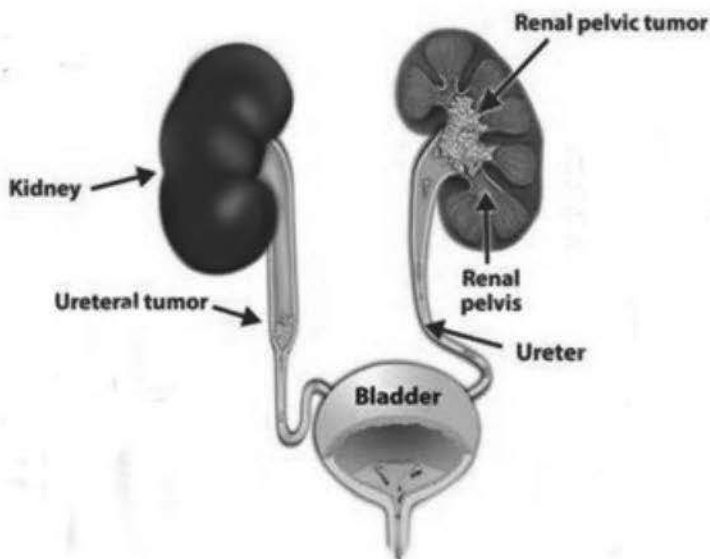
Although you may have no symptoms of UTUC, some signs and symptoms are similar to those of bladder cancer:

- Blood or blood clots in the urine
- Pain in the lower back, side or stomach

Less common symptoms may include:

- Weight loss and loss of appetite
- Bone pain
- A mass in your side or abdomen

It’s important to note that you may not have all these signs and symptoms. Also, some of the symptoms listed above may be signs of other conditions. Consult your health care provider if you are concerned about any of these symptoms.



## HOW IS UPPER TRACT UROTHELIAL CARCINOMA DIAGNOSED?

If your family physician suspects you have some type of cancer of the urinary system, you should be referred to a **urologist**, a specialist in urinary issues. The urologist will likely start by taking a health history, examining you, and ordering blood and/or urine tests.

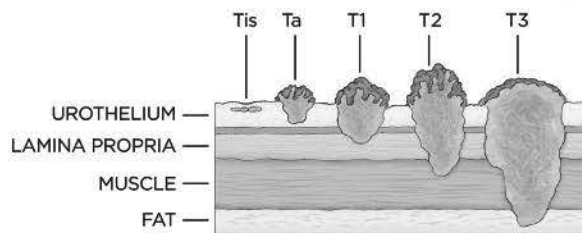
The next step in diagnosis is usually a CT (computerized tomography) scan. To help see any tumours clearly, the scan may be done using a contrast dye. An MRI (magnetic resonance imaging) scan may also be used. If you are unable to get a CT or MRI, an ultrasound can be considered.

**Cystoscopy** may be recommended as patients with UTUC are at risk for bladder cancer as well. A cystoscope is a special fibre optic tool inserted through your urethra to look inside the bladder and urinary tract. This is typically done with local anesthesia.

To get a more detailed look inside your upper urinary tract, the urologist may recommend **ureteroscopy**, which is similar to a cystoscopy, but looks inside the ureter and kidney. Ureteroscopy is usually done under general anesthetic. A sample of tissue may be taken (a biopsy) for analysis in a laboratory.

## STAGING AND GRADING

Laboratory analysis of the tissue taken out during the ureteroscopy is used to determine the type and grade of the cancer. Grading describes how aggressive the cancer looks under the microscope. The CT or MRI scan together with the biopsy determines the stage of the cancer, which describes how deeply the cancer has grown into the kidney and whether there is any spread to other parts of the body.



## STAGING (TNM)

Staging includes a **Tumour (T) category** that describes the tumour itself:

**T0** - No evidence of tumour

**Tis** - Carcinoma in situ (flat tumour).

**Ta** - Non-invasive papillary carcinoma.

**T1** - The tumour is into the subepithelial connective tissue

**T2** - The tumour has grown into the muscle

**T3** - The tumour has spread beyond the muscle into the surrounding fat or into the kidney tissue itself

**T4** - The tumour has spread to adjacent organs or through the kidney into the fat

In addition, the **Node (N) category** describes whether or not the UTUC has spread to lymph nodes near the tumour itself. The N stage categories include: NX, N0, N1, and N2.

The **Metastasis (M) category** describes whether the cancer has spread to organs and/or lymph nodes in other parts of the body that are more distant from the bladder. The category M1 means that the cancer has spread to distant parts of the body and the category M0 means that the cancer has not spread to distant parts of the body.

Bear in mind that it can be somewhat difficult for your medical team to know the true extent of your tumour without surgery. "Clinical staging" describes the extent of tumour determined by the ureteroscopic biopsy and the CT or MRI scan. "Pathological staging" may be different, as it is determined by laboratory analysis after surgical removal of the tumour and surrounding tissue.

## GRADING

The pathology report following your ureteroscopy will generally confirm the diagnosis of urothelial cancer and show whether your tumour is “high grade” or “low grade.”

## IMPORTANT

Keep a copy of the pathology report, which will confirm the diagnosis and tell you the grade of the tumour. The pathology report will not tell you where else the cancer is or may be.

## HOW IS UPPER TRACT UROTHELIAL CANCER TREATED?

There are three options for treating UTUCs: surgery, chemotherapy and radiation. Which treatment, or combination of treatments, you and your doctor choose will be based on several factors, such as the grade and stage of the tumour, your age, overall health and medical history.

## SURGERY

Surgery is the most common option for treating UTUC. There are three types of surgery for UTUC:

1. Removal of the entire kidney and ureter (called “**nephroureterectomy**”). This surgery is performed for most high-grade tumours and for extensive low-grade tumours in the kidney and the upper ureter. At the discretion of your surgeon, the surgery may be done by making one or more larger incisions in the abdomen (the “open” method) or it may be done by inserting instruments and a camera through smaller incisions (“laparoscopically”). In some centres the laparoscopic approach employs a surgical robot (“robotic”). This surgery will leave you with only one kidney but, if your remaining kidney is working well, you shouldn’t need dialysis.
2. Removal of a segment of the ureter or kidney (called “**segmental resection**”). In select cases, your surgeon may decide to spare the kidney.

This is more commonly done in patients with pre-existing kidney problems and tumours that are relatively confined or low grade, and especially when the tumour is in the lower ureter. In these situations, the part of the urinary tract that is cancerous is removed and the remaining part is reconstructed.

3. Destruction of the tumour by laser through the ureteroscope (called “**endoscopic ablation**”). This method is used for tumours that are small, non-invasive and low-grade.

## CHEMOTHERAPY

Chemotherapy uses drugs to kill cancer cells. It can be used for treatment of UTUC in two ways:

1. Chemotherapy can be delivered into the vein (intravenous) for invasive UTUC before or after surgery, and as the main form of treatment of patients who have UTUC that has spread to other organs (“metastatic”).
2. Chemotherapy can be delivered through a catheter to the inside of the kidney, ureter or bladder to treat low grade UTUC or prevent recurrences in the bladder after surgery.

Intravenous chemotherapy can be associated with various side effects. Your care team will review all of the risks with you before starting treatment and will consider your cancer history and past medical history when deciding on the best choice for you.

Treatment of metastatic UTUC is mostly the same as treatment of metastatic bladder cancer. This can involve chemotherapy, immunotherapy, and newer targeted therapies.

## RADIOTHERAPY

Radiotherapy is rarely used for UTUC. The role of targeted (“stereotactic”) radiotherapy is being studied and may play a more important role in the future.

## HOW CAN YOU SUPPORT YOUR TREATMENT?

Diagnosis and treatment of UTUC can be challenging. It is vital that you ask for support and maintain a healthy lifestyle.

Regular exercise is important and recommended at every stage of your treatment. It reduces cancer and treatment-related fatigue and improves quality of life.

To manage side effects from treatment it is also essential that you eat well during your treatment. Try to limit alcoholic drinks, processed foods and increase your intake of plant-based foods including fruits, vegetables and legumes.

## CLINICAL TRIALS

There are several new therapies for UTUC, some of which may be approved by Health Canada, but may not yet be covered by your provincial or private drug program. Others may only be available through a clinical trial or a patient access program.

A clinical trial is a research study that tests how well a new medical approach works in people with a certain disease. 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 that might not be available to you otherwise. Participation in a clinical trial is voluntary and you may withdraw from them at any time.

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 urothelial under “Select a Cancer Type.” You may need to select “Show More,” if urothelial does not display on the list you see. You can also search by province, city or trial centre.

You can also go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) to see what is going on in North America.

It’s very important that you discuss with your medical team whether a clinical trial is right for you. Talk to your doctor about the options and the right treatment program for you.

## SUPPORT US

Individual donations are greatly appreciated, and tax receipts are issued for donations of \$20 or more. Donations can be made online at [www.bladdercancercanada.org](http://www.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 [www.BCCwalk.ca](http://www.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!**

## 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:  
[www.bladdercancercanada.org](http://www.bladdercancercanada.org).

## HELPFUL WEBSITES:

- **Bladder Cancer Canada**  
[www.bladdercancercanada.org](http://www.bladdercancercanada.org)
- **Cancer Network**  
<https://www.cancernetwork.com/view/urothelial-and-kidney-cancers>
- **Yale Medicine**  
<https://medicine.yale.edu/urology/programs/genitourinary/upper/>
- **Mayo Clinic**  
<https://www.mayoclinic.org/diseases-conditions/ureteral-cancer/symptoms-causes/syc-20360721>



**Contact us:**

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You can also follow us on

**f/BladderCancerCanada** **t/BladderCancerCA**

**@BladderCancerCanada**

We'd like to thank those on our Medical Advisory Board who provided the content and review of this Guidebook.

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



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We are grateful to whose generous financial support has made this Guidebook possible.

