

Bladder Cancer Handbook



ROGEL CANCER CENTER
MICHIGAN MEDICINE

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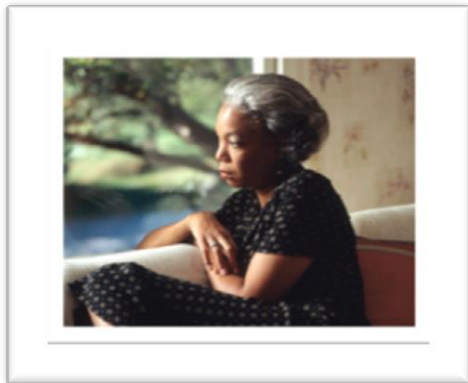
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Understanding Your Diagnosis



Each year in the U.S., more than 70,000 new cases of bladder cancer are found. Bladder cancer is the fourth most common cancer in men and ninth in women. Bladder cancer, if found early, has a very good chance of being cured. There are more than 500,000 bladder cancer survivors in the U.S. today.

If your doctor has told you that you have bladder cancer, you probably have a lot of questions and concerns. We know that getting a diagnosis of cancer is very hard. However, learning about treatment options for bladder cancer and how to care for yourself can help you take an active part in making choices about your care. There are many oncology providers at the University of Michigan Rogel Cancer Center that are here to support you and your family as you go through your treatment.

Providing the right support for you and your family starts with treating you like you are part of our own family. That's the commitment of the Patient & Family Support Services (PFSS) Program at the University of Michigan Rogel Cancer Center. Cancer affects not only the body, but the whole person and the whole family. PFSS and the entire Rogel Cancer Center are here to support you. Please review the ***Patient & Family Support Services Handbook*** you received in your ***New Patient Toolkit***. If you have any questions about the services listed in the Handbook or how to access them, talk with your oncology team.

Our support starts with giving you and your family up-to-date patient education on bladder cancer. The ***Bladder Cancer Handbook*** may be used in combination with the other educational materials you may receive from your oncology provider as part of your treatment.

In addition to the resources listed above, you may want to read the ***Patient Rights and Responsibilities*** brochure. The information in this brochure may be helpful to you during your treatment. This brochure is widely available throughout the Rogel Cancer Center.

About This Handbook

This Handbook gives you a broad overview of bladder cancer and treatment choices. Many people find it helpful to make a list of questions to take with them to their oncology doctor visit. We've listed a few below to get you thinking.

It's helpful to take notes and to be organized as possible, so we have also given you the ***New Patient Toolkit*** to help organize your visits. Also, you may want to have a family member or friend go with you when you talk with your oncology doctor or health care team. They can take notes, ask questions, or just listen and be supportive.

Questions to ask your doctor

- Do I have bladder cancer?
- What kind of bladder cancer do I have?
- What is the stage of my cancer?
- What are my treatment options?
- What do you suggest? Why?
- Has the bladder cancer spread?
- Can I speak to a patient who has gone through this type of treatment?
- What are the risks of each treatment?
- How will this treatment affect my sex life?
- Will I need extra tests?
- Can any treatments cure my bladder cancer?

What to do before your doctor visit

Here are some things to think about and to organize before you visit your doctor:

- Know of any pre-visit restrictions. For example, ask if there is anything you need to do before such as limits on eating and drinking.
- Make a list of all medications including vitamins and supplements and when you take them. Bring this list with you to your appointments.
- Write down your pharmacy name and phone number.
- Write down any symptoms you are having.
- Consider bringing a family member or friend for support and/or to ask questions.
- Write down any questions to ask your doctor (see page five for a list of questions).



We know this is a lot of information to understand and remember. At the end of the booklet we've given you place to write your questions.

Important Phone Numbers

If you have any questions, call the University of Michigan Rogel Cancer Center Urology Oncology Clinic at **734-647-8903, Monday thru Friday from 8:00 am – 5:00 pm.**

If there are any concerns that need to be addressed after business hours or on weekends, call **734-936-6267 and ask to speak with the Urology Resident on call.**

If you need to be seen by a doctor as an emergency, go to the nearest Emergency Department and have the doctor **call the University of Michigan Urology Resident on call via M-Line at 800-962-3555.**

University of Michigan Programs and Services

Center for Sexual Health	734-647-8903
Nutrition Clinic	734-936-6000
Patient & Family Support Services	877-907-0859
Physical Therapy	800-888-9825
Social Work	734-936-7175
Urologic Oncology Clinic	734-647-8903

Appointments

Cancer Center Infusion (Use only for same day appointments, if you will be late or need to cancel.)	734-647-8908
Enterostomal Therapy	734-936-7030
Endoscopy	734-615-5123 or 877-334-2943
Nuclear Medicine Department	734-936-5090
Radiology Department	734-936-4500
Radiation Oncology Department	734-936-4320
Urologic Oncology Clinic	734-647-8903

Overview

Normal Bladder

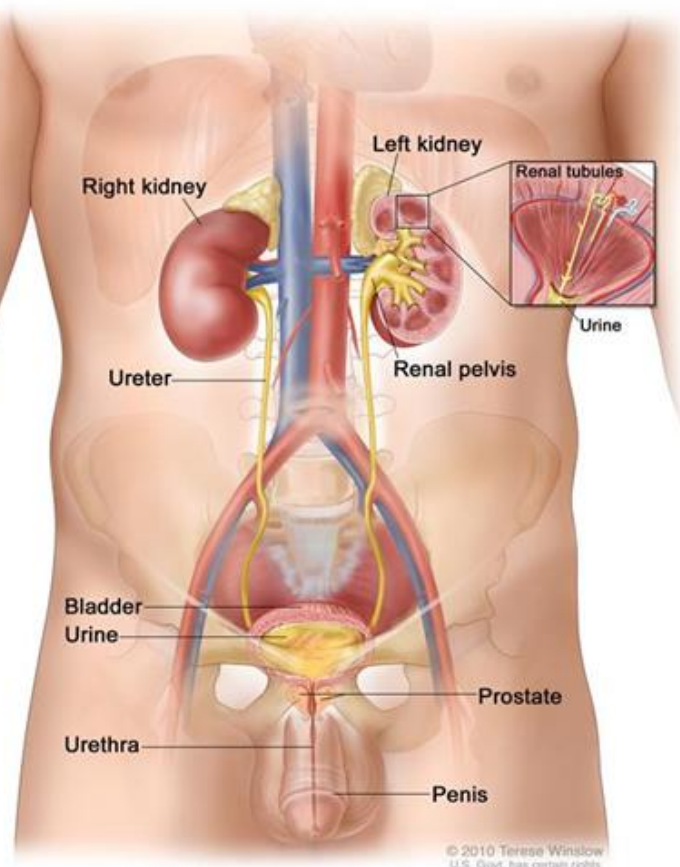
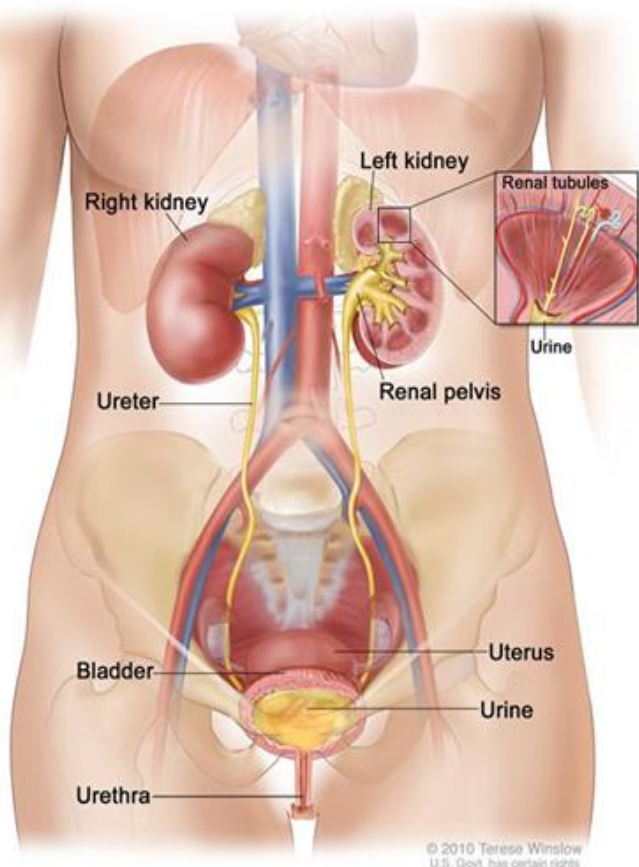
Your bladder is a hollow muscular *organ* in the lower *abdomen*. It stores urine, the liquid waste made by the kidneys.

Your bladder is part of the *urinary tract*. Urine passes from each kidney into the bladder through a long tube called a *ureter*. Urine leaves the bladder through a shorter tube called the *urethra*.

The wall of the bladder has four main layers:

- The inner layer is called the lining. This lining is made up of cells called *urothelial* or *transitional cells*. This layer is called the *urothelium* or *transitional epithelium*.
- Under the *urothelium* is a thin layer of connective tissue, blood vessels, and nerves, which is called the *lamina propria*.
- Next is a thick layer of muscle called the *muscularis propria*.
- Outside of this muscle, a layer of fatty connective tissue sets apart the bladder from other nearby organs.

It is important to know about the layers of your bladder, because bladder cancer most often starts in the *urothelium*. As the cancer grows or spreads into the other layers in the bladder, it becomes more progressive.



These pictures show the bladder and nearby organs in women and men.

Adapted, with permission, from "What to Know Bladder Cancer" National Cancer Institute.

Cancer Cells

Cancer starts in cells, which are the building blocks that make up tissues. Tissues make up the bladder and other organs in your body.

Normal cells grow and divide to form new cells as the body needs them. When normal cells grow old or get hurt, they die, and new cells replace them.

Sometimes this process goes wrong. New cells form, when the body does not need them, and old or hurt cells don't die as they should. The build-up these extra cells sometimes forms a mass of tissue called a growth or a *tumor*.

Tumors in the bladder can be *benign* (not cancer) or *malignant* (cancer). This overview of bladder cancer will focus on malignant cancer.

Bladder cancer cells can spread by breaking off from the original tumor. They can spread through the blood vessels to the liver, bones, and lungs. Also, bladder cancer cells can spread through *lymph vessels* to nearby *lymph nodes*. After spreading, the cancer cells may attach to other tissues and grow to form new tumors. For more facts about bladder cancer that has spread, see pages 12-13 in this handbook.

Risks of Bladder Cancer:

- **Smoking.** If you smoke, you are three times more likely to get bladder cancer than a non-smoker.
- **Chemicals in the workplace.** Some people have a higher risk of bladder cancer because they have worked around cancer-causing chemicals. Workers in the dye, rubber, leather, textiles, and paint trades are at higher risk for developing bladder cancer. Other workers who have a greater risk are painters, machinists, printers, hairdressers (hair dye), and truck drivers (diesel fumes).
- **Personal history of bladder cancer.** People who have had bladder cancer have a greater risk for getting the disease again.
- **Family history of bladder cancer.** People with family members who have had bladder cancer can have a slightly greater chance of getting the disease.
- **Age.** Bladder cancer is more common in people aged 55 and older.
- **Gender.** Bladder cancer is more common in men than women.
- **Life-long bladder irritation and infections.** People who have had a lot of bladder infections are at a greater risk of getting bladder cancer.
- **Low fluid intake.** Not drinking enough fluids may add to the risk.
- **Arsenic.** Arsenic is a poison that raises the risk of bladder cancer. In some parts of the world, arsenic may be found at high levels in drinking water. In the U.S., the chance of being exposed to arsenic depends on where you live and whether you get your water from a well or a sanitation system.

How Can I Reduce My Risk of Bladder Cancer?



Don't smoke. Smoking is the single most important known risk for bladder cancer. Smoking increases your risk of bladder cancer by three times. It is never too late to stop using tobacco. If you would like help to quit smoking or the use of other tobacco products, please call the MHealthy Tobacco Consultation Service 734-998-6222 or www.mhealthy.umich.edu/tobacco.

- If you smoke, talk to your doctor about a plan to help you stop. Support groups, medications, and other methods may help you quit.
- Take precautions with chemicals. If you work around chemicals, follow all the safety instructions to avoid exposure.
- Drink a lot of water. Drinking water and other fluids may weaken toxic matter that concentrate in your urine and flush them out when you pass urine.
- Eat foods like fresh fruits, vegetables, whole grains and beans. These foods can help you maintain your weight and fight against cancer.

What Are the Signs and Symptoms of Bladder Cancer?

Blood in the urine:

- Blood in the urine does not mean you have bladder cancer. You may have blood in your urine if you have a urinary tract infection, benign tumors, kidney stones or other benign kidney diseases. But it is important to have it checked out by a doctor. It is not normal to have blood in your urine.

Symptoms of irritation or changes in bladder habits:

- Feeling an urgent need to empty your bladder.
- Having to empty your bladder more often.
- Feeling pain when you empty your bladder.
- Feeling the need to empty your bladder without results.
- Needing to strain (bear down) when you empty your bladder.

What is Bladder Cancer?

Bladder cancer is a disease in which malignant cells grow in the tissues of your bladder. When bladder cancer is found at an early stage, it is treatable. Many bladder cancers are found at this stage. However, bladder cancer often returns, even when it is found at an early stage. That's why it is important to keep on testing for bladder cancer.

Types of Bladder Cancer

Transitional cell (urothelial) carcinoma. This is the most common form of bladder cancer. It represents roughly 95% of bladder cancers.

Urothelial cells also line other parts of the urinary tract as well as the kidneys, the ureters, and the urethra. Patients with bladder cancer sometimes have cancer in the lining of the kidneys, ureters, or urethra. It is important to have the whole urinary tract checked for cancer if you have been found with any cancer in any part of the urinary system.

Bladder cancers are often described based on how far they have invaded into the wall of the bladder:

- **Non-invasive:** cancer cells are still in the inner layer of cells and have not grown into the deeper layers.
- **Invasive:** cancer cells have grown into the lamina propria or even deeper into the muscle layer.
- **Metastatic:** cancer cells from the main tumor have spread to other parts of the body.

Bladder cancer can be described as *superficial or non-muscle invasive*. If you hear these terms it means the cancer has not spread into the muscle and is non-invasive.

Transitional cell carcinomas are also split into two groups. The grouping decides how the cells grow.

Papillary carcinomas: Grow in finger-like projections from the inner surface of the bladder toward the hollow center.

- Urothelial papilloma – Non-cancerous (benign) tumor.
- Papillary urothelial neoplasm of low malignant potential (PUNLMP) – Very slow growing and unlikely to spread.
- Low grade papillary urothelial carcinoma – Slow growing and unlikely to spread.
- High grade papillary urothelial carcinoma – More quickly growing and more likely to spread.

Flat carcinomas: Do not grow toward the hollow part of the bladder. It is a flat tumor. You may also hear it called non-invasive flat carcinoma or a flat carcinoma in situ (CIS).

Squamous cell carcinoma: Roughly 1% to 2% of bladder cancers are squamous cell carcinomas. Nearly all squamous cells are invasive.

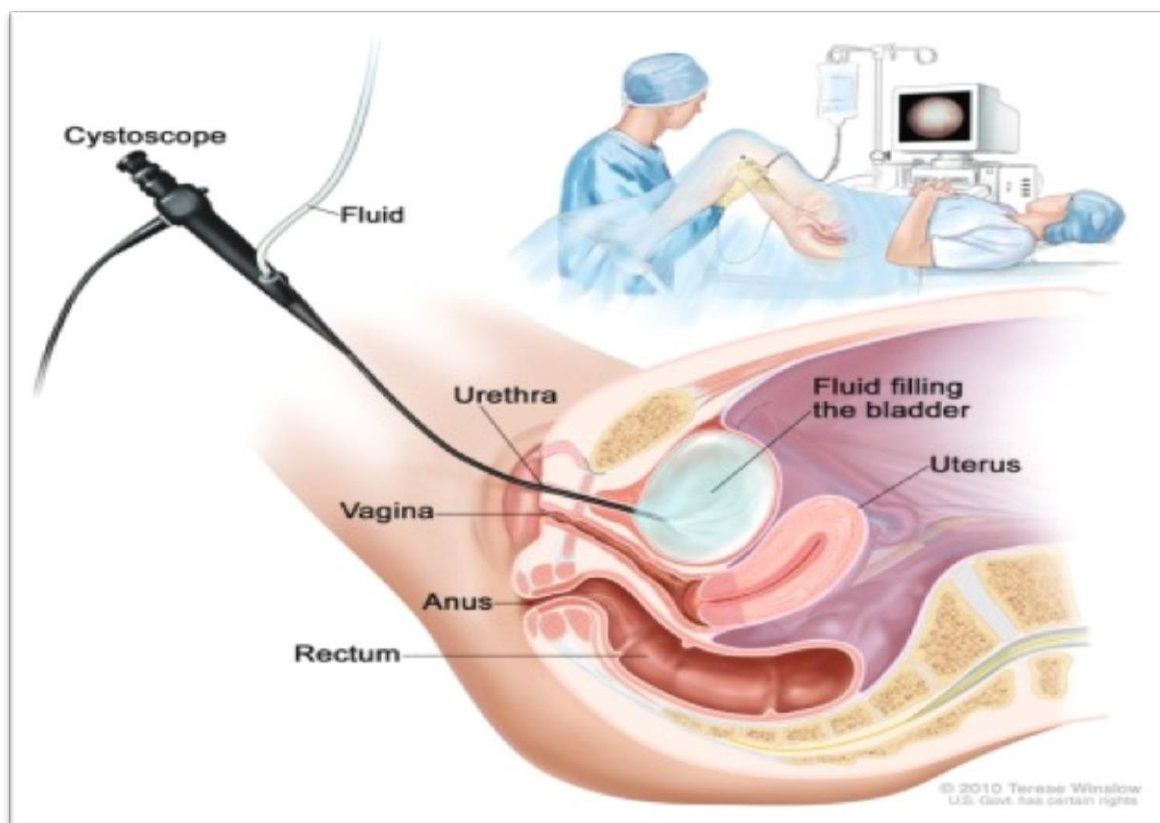
Adenocarcinoma: Roughly 1% of bladder cancers are adenocarcinomas.

Small cell carcinoma: Roughly 1% of bladder cancers are small cell carcinomas. These cancer cells can grow quickly and are most often treated with chemotherapy.

Sarcoma: Sarcomas start in the muscle of the bladder. This cancer is very rare in the bladder.

How Do You Test for Bladder Cancer?

Physical exam and medical history: Your doctor will talk to you about your medical history and do a physical exam. The medical history looks for any risk factors for bladder cancer and the physical exam gives more information about signs of bladder cancer.



Adapted, with permission, from "What to Know Bladder Cancer" National Cancer Institute.

Cystoscopy: If bladder cancer is suspected, your doctor will closely look at the inside of your bladder. To do this, he/she will place a cystoscope which is a small tube with a lens, a light and camera through the opening of your urethra and advance it into your bladder. This can be performed in the clinic or in the operating room. If an atypical area or growth is seen, then the doctor will send it off to be biopsied. The cystoscopy is the gold standard for finding bladder cancer.

Bladder biopsy: During your cystoscopy, your doctor will remove any tumors and will take sample cells from the bladder to be looked at under the microscope. These results can take up to five days to complete.

Urine cytology: A sample of your urine is sent to the lab to be looked at under a microscope to see if it has any pre-cancer or cancer cells. It can take up to five days for you to get your test results.

FISH (Fluorescence in situ hybridization): Is a urine-based genetic test for the diagnosis and surveillance of bladder cancer. It gives the most sensitive detection of bladder cancer available today, and it can spot bladder cancer up to six months sooner than other tests.

Urine culture: If you are having urinary symptoms, this test will be performed to see if you have a urinary tract infection. This test can take up to two to three days for results.

Imaging Tests

Computerized tomography (CT) Urogram: Is a CT of the kidneys, ureters, and bladder. This gives your doctor detailed information about the size, shape and position of any tumors in the urinary tract.

Intravenous pyelogram (IVP): Is an x-ray of the urinary system taken after a special dye has been injected into your vein. The dye outlines these organs on the x-ray and helps find urinary tract tumors.

Retrograde pyelogram: A catheter is placed through the urethra and up into the bladder or into a ureter. Then a dye is injected through the catheter to make the lining of the bladder, ureters and kidneys easier to see.

Chest X-ray: Chest x-ray may be done to look for bladder cancer which has spread to the lungs.

Ultrasound: Ultrasound uses sound waves to make pictures of the organs inside your body. It can be useful in deciding the size of the tumor and whether it has spread beyond the bladder to nearby organs or tissues.

Bone scan: A bone scan looks to see if cancer has spread to the bones. Doctors do not usually order this test unless you have symptoms of bone pain or if blood tests show the cancer might have spread to your bones.

MRI (Magnetic resonance imaging): A MRI looks to see if cancer has spread outside of the bladder into nearby tissues or lymph nodes. A special MRI of the kidneys, ureters, and bladder is known as a MRI urogram.

Grade

If cancer cells are found in the tissue sample from the bladder, a pathologist studies the sample under a microscope to learn the grade of the tumor. The grade tells how much the tumor tissue differs from normal bladder tissue.

Tumors with higher grades tend to grow faster than those with lower grades. They are also more likely to spread. Your doctor uses this grade along with other factors to decide your treatment options.

Staging

If bladder cancer is diagnosed, the next step is to choose the best way to treat it. To help do this, your doctor checks how deep the cancer cells have grown and whether it has spread (the cancer stage).

TNM Staging of Cancer

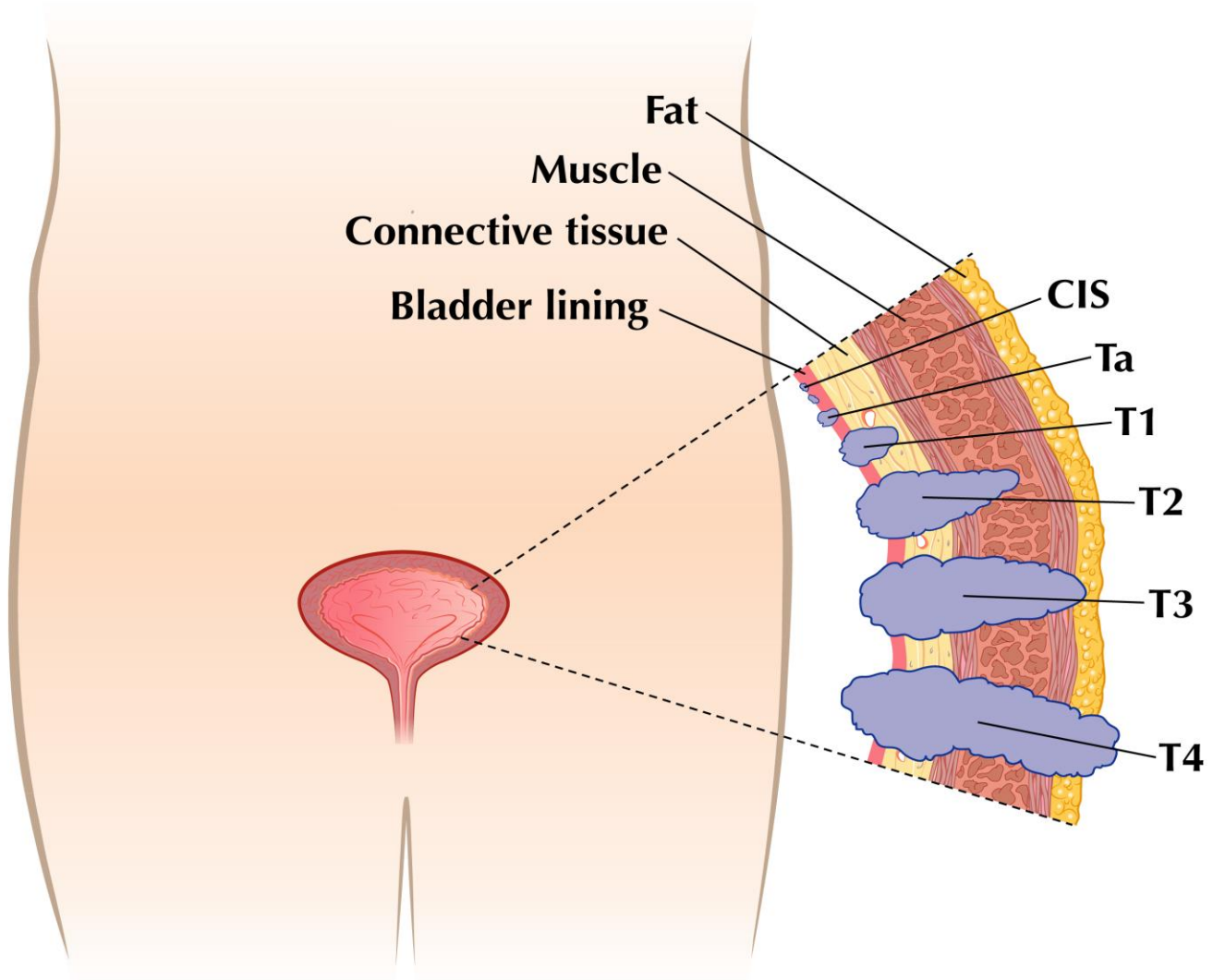
The TNM staging system is based on the size and/or extent of the primary tumor (T), whether cancer cells have spread to nearby (regional) lymph nodes (N), and whether metastasis (M), or the spread of the cancer to other parts of the body has occurred. Doctors find the T stage by looking at the grade of the cancer cells after a biopsy, examination of the bladder under anesthesia, and a CT or MRI scan.

Here are the stages of cancer:

- CIS (also called Tis) - very early, high grade, cancer cells are only in the innermost layer of the bladder lining.
- Ta - the cancer is just in the innermost layer of the bladder lining.
- T1 - the cancer has started to grow into the connective tissue under the bladder lining.
- T2 - the cancer has grown through the connective tissue into the muscle.
- T2a - the cancer has grown into the superficial muscle.
- T2b - the cancer has grown into the deeper muscle.

- **T3** - the cancer has grown through the muscle into the fat layer.
- **T3a** - the cancer in the fat layer can only be seen under a microscope (microscopic invasion).
- **T3b** - the cancer in the fat layer can be seen on tests, or felt by your doctor during an exam under anesthesia (macroscopic invasion).
- **T4** - the cancer has spread outside the bladder.
- **T4a** - the cancer has spread to the prostate, uterus or vagina.
- **T4b** - the cancer has spread to the wall of the pelvis or abdomen.

Bladder Cancer Staging



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Treatment for Bladder Cancer

Bladder cancer is treated in many different ways using treatments that are the standard of care. These are the best proven treatments available. Patients are also encouraged to consider clinical trials as an option. A clinical trial is a research study to test new treatments to measure if it is useful and safe. They are an important option for people with all stages of bladder cancer.

Treatment choices and recommendations depend on many factors, including the stage and grade of bladder cancer, type, side effects of treatment, patient's overall health and the patient's choice. Your doctor will go over your treatment plan with you.

Descriptions of the most common treatment options for bladder cancer are listed below. Once your treatment plan has been developed by your oncologist, you and your family members or friends will receive patient education and instructions on how to care for yourself during treatment.

Surgery

Surgery to remove the tumor (Transurethral resection): Is the removal of the tumor and surrounding tissue during an operation. This procedure is performed under anesthetic. Tissue is sent off to pathology to test for type of cancer and depth of cancer. You may have painful or bloody passing of urine up to five days after the procedure.

Partial cystectomy: The surgeon removes only a part of the bladder containing cancer cells. This may be an option if your cancer is limited to one part of the bladder that can be easily removed without harming bladder function.

Cystectomy (removal of entire bladder): A radical cystectomy is an operation that removes the entire bladder, along with lymph nodes.

In men, along with the removal of the bladder and lymph nodes the prostate and seminal vesicles are usually removed, as well. As a result, men often have

erectile dysfunction. With robotic surgery, men who want to keep their ability to have an erection are sometimes able to have a nerve-sparing surgery, which lowers the risk of nerve damage. This method is only available to men who have no signs of cancer in the bladder neck or prostatic urethra, no carcinoma in situ and no signs of prostate cancer.

In women, along with the removal of the bladder and lymph nodes the uterus, ovaries and part of the vagina are usually removed as well. As a result, women will not be able to get pregnant and will go into premature menopause. A highly selective group of women, with robotic surgery, can have nerve-sparing surgery. This involves careful removal of tissue on each side of the vagina, where nerves responsible for sexual function are found. Nerve-sparing surgery may help to stop vaginal dryness, pain with intercourse, and loss of the ability to have an orgasm.

Because bladder cancer surgery may affect your sex life, it may be helpful for you and your partner to talk about your feelings. You can talk about other ways to share intimacy during and after treatment. If you'd like to talk to a counselor about your feelings, your doctor can refer you.

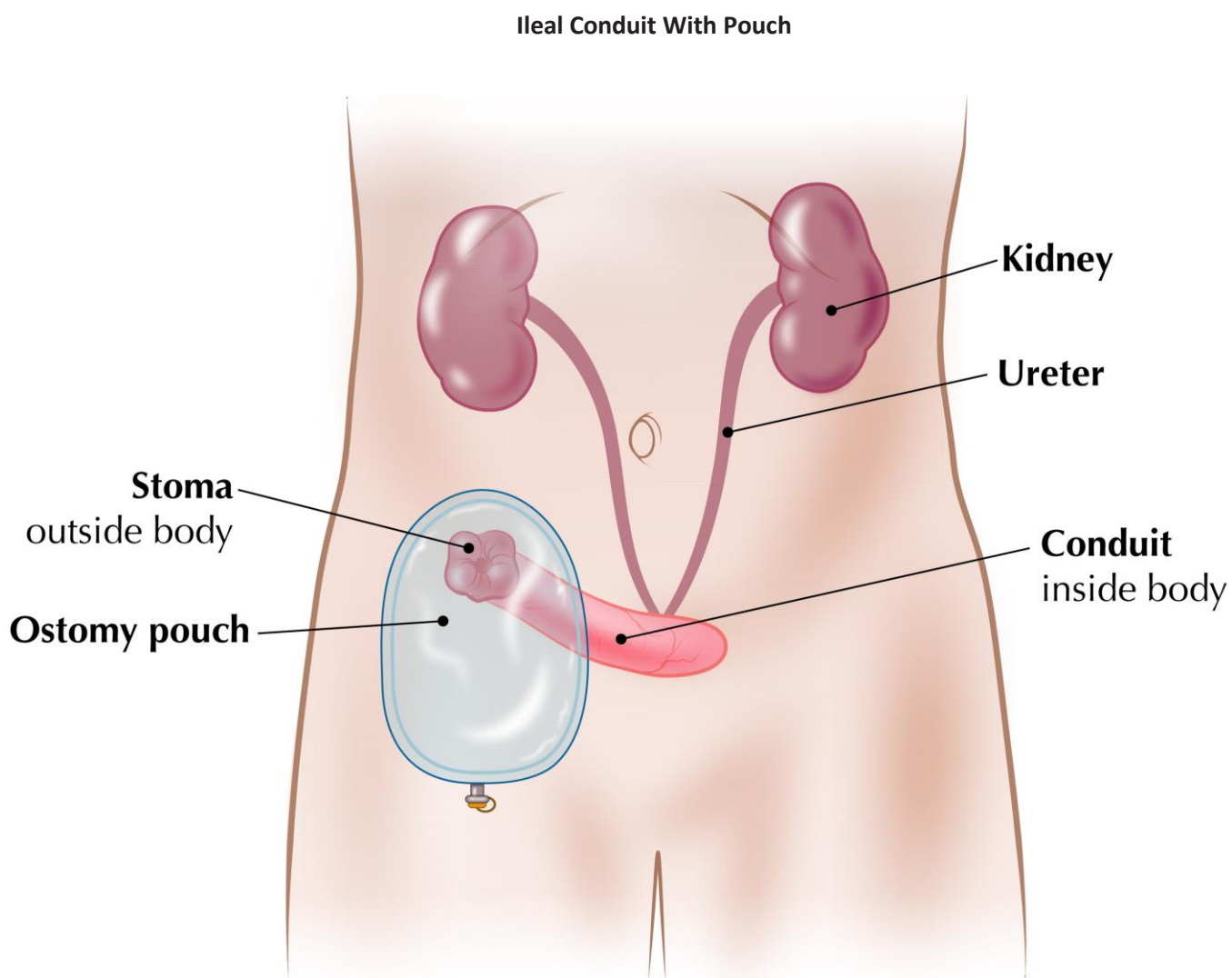
When the entire bladder is removed, the surgeon makes another way for urine to be collected from the kidneys and stored. You may wear a flat pouch outside of your body under your clothes or the surgeon may use part of your intestine to create a pouch inside your body.

Depending on your treatment plan, you will receive an additional handbook on one of the following bladder surgeries:

- Ileal Conduit
- Indiana Pouch
- Neobladder

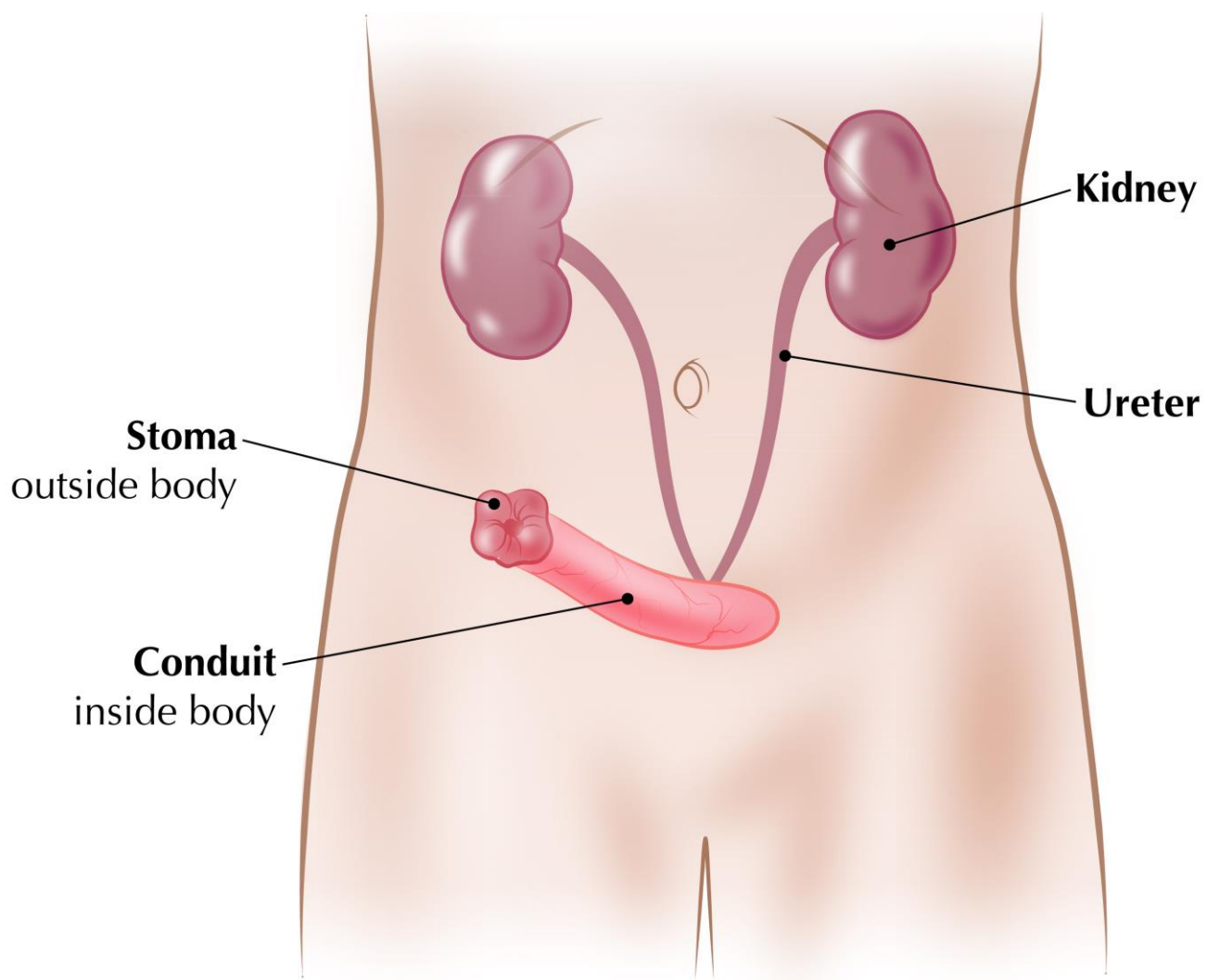
Surgery to create a new way for urine to leave the body

Ileal Conduit: The surgeon takes a short segment of the small intestine and connects one end to the stoma. The small opening in the abdomen area is called the stoma. The ureters (normally attached to the bladder) are attached to the other end of the segment of the small intestine. You will wear a pouch over the stoma to collect the urine. The ostomy pouch adheres to the body which is over the stoma using a wafer or flange.



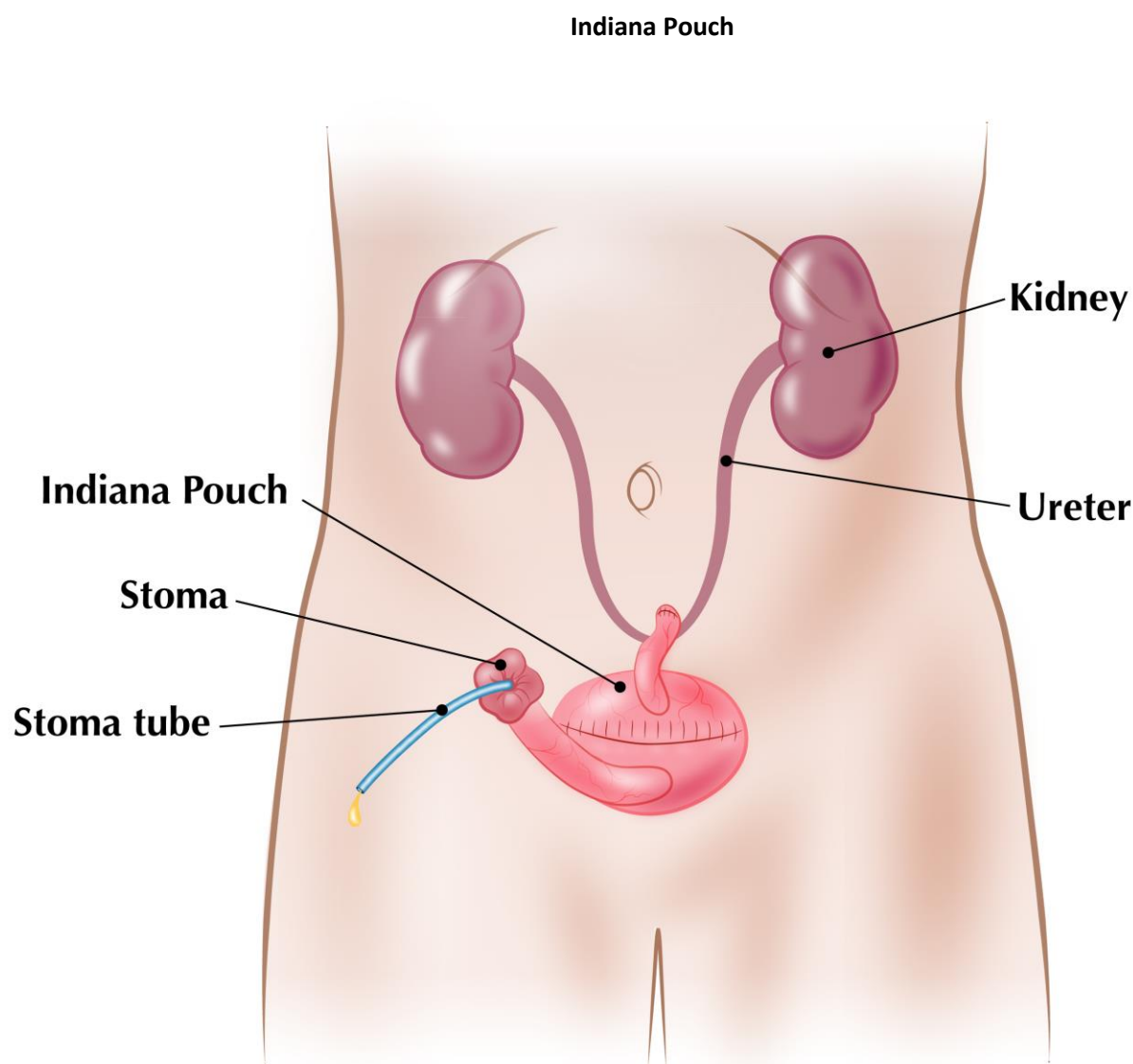
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Ileal Conduit Without Pouch



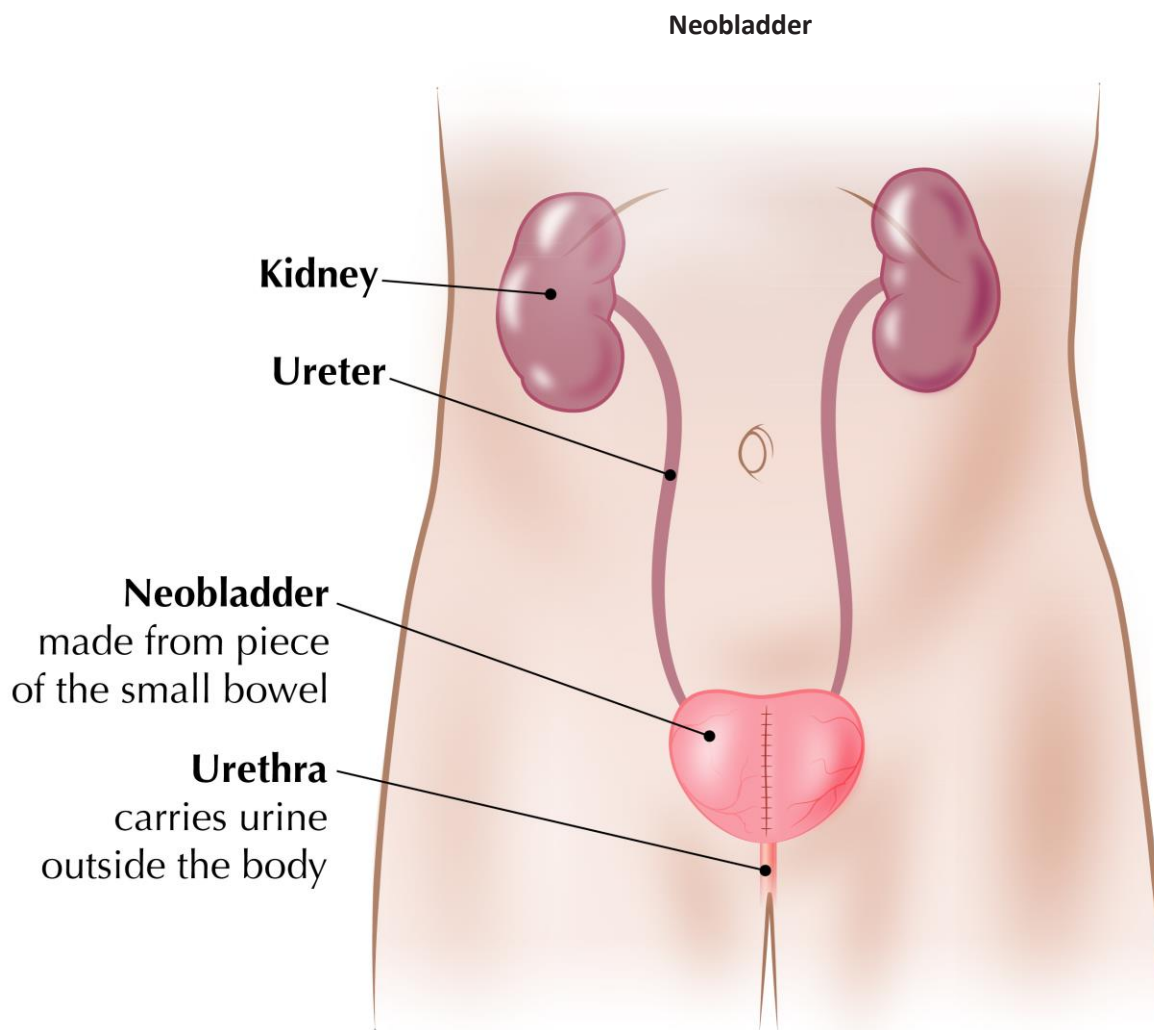
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Indiana Pouch: An Indiana Pouch is a pouch made from part of your bowel to store urine. The surgeon will create a pouch which is brought out through an opening made on your abdomen. This opening is called a stoma. Using a catheter, you will drain urine out of the pouch at certain times.



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Neobladder: A neobladder replaces the bladder by using part of the large bowel. The surgeon will create a new bladder like reservoir from a piece of the large bowel and attach it to the neck of the urethra. It will store your urine and allow you to urinate through the urethra much like you did before your surgery. You may need to use a catheter to drain all the urine from your neobladder.



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In addition to surgery, there are many other treatment options for bladder cancer. We've listed a few of the most common treatments in this booklet. Depending on your treatment plan, you will receive more in-depth information on your treatment and how to care for yourself.

Systemic Chemotherapy

Chemotherapy is prescribed by a medical oncologist. A medical oncologist is a doctor who specializes in treating cancer with medication. A patient with muscle-invasive bladder cancer which is found only in the bladder often get chemotherapy before (neo adjuvant therapy) or after (adjuvant therapy) cystectomy to reduce the risk of the cancer spreading to other parts of the body. If your doctor decides that chemotherapy is the right choice to treat your bladder cancer, you will receive a handbook on chemotherapy.

Radiation

Radiation can be used on select patients for bladder preservation or in patients with small cell bladder cancer that is sensitive to chemo-radiation. Radiation therapy uses high-energy beams aimed at your cancer to kill the cancer cells. Radiation therapy can be used after surgery to kill cancer cells that might stay. Radiation therapy is sometimes combined with chemotherapy. If your doctor decides that radiation is the right choice to treat you bladder cancer, you will receive a handbook on radiation therapy.

Immunotherapy or Biological Therapy

Immunotherapy works by using your body's immune system to fight cancer cells. This treatment is given through your urethra and straight into the bladder by a small catheter. If your doctor decides that this how your cancer will be treated, you will receive a separate handbook on immunotherapy.

Immunotherapy drugs used to treat bladder cancer include:

(Bacille Calmette-Guerin) BCG

- Is a bacterium used in tuberculosis vaccines. This bacterium appears to start a local immune reaction against the tumor. Immunotherapy with BCG stops recurrence in up to 67% of superficial bladder cancer.
- BCG is used to treat non-muscle invasive bladder cancer. The BCG kills cancer cells and stops recurrence of bladder cancer. BCG is instilled directly into your bladder by a catheter.
- BCG is given initially once a week for six weeks. Followed by a cystoscopy in four to six weeks. After the cystoscopy, your oncology doctor may order maintenance BCG. Maintenance BCG is given once a week for three weeks. You may have BCG treatments for up to three years.

Mitomycin C

- Is an anti-tumor antibiotic used specifically in the treatment of cancer. It interferes with the multiplication of cancer cells.
- Mitomycin C is a purple-colored mixture that attacks cancerous cells when placed into the bladder. It does little harm to your normal, healthy bladder lining. It is a chemotherapy drug, but because it is placed into your bladder with a Foley catheter and not injected into your veins, you will not get the side-effects often tied to intravenous (IV) chemotherapy, such as vomiting, nausea, and hair loss.
- Treatment usually involves coming into the outpatient clinic once a week for six weeks for treatment. This is followed-up by a cystoscopy in four to six weeks. After your cystoscopy, your doctor will decide your plan of care.
- The process may take one to two hours and the drug itself stays in the bladder for one hour and is then removed by a Foley catheter or leaves the bladder when you empty your bladder of urine.

Gemcitabine/Gemzar

- Is used to treat non-muscle invasive bladder cancer. Gemcitabine kills cancer cells and stops the recurrence of bladder cancer.
- Gemcitabine is instilled straight into your bladder by a catheter. The usual course of treatment is once a week for six weeks or maintenance doses as decided by your doctor.

Recovery

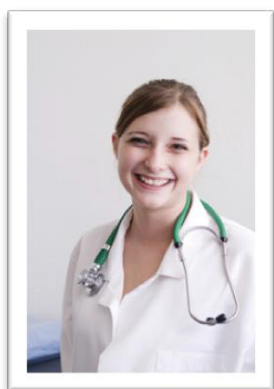
Your oncology team will help you return to normal activities as soon as possible. Your goals for recovery will depend on the extent of your disease and the type of treatment you received for your bladder cancer.

Nutrition

It's important for you to take good care of yourself before, during, and after your cancer treatment. Taking care of yourself includes eating well so that you get the right amount of calories to maintain a healthy weight and so that you have enough energy.

Sometimes during or soon after treatment, you may not feel like eating. You may be tired, and foods that once tasted good, may no longer have that appeal. In addition, the side effects of treatment (such as nausea, vomiting, poor appetite, or mouth sores) may make it hard to eat. Your healthcare team may refer you to a registered dietitian who can suggest ways to help you meet your nutrition needs.

Follow-up care



Because bladder cancer may return, you'll need regular check-ups after treatment for bladder cancer. These check-ups help to make sure that any changes in your health are noted and treated right away. If you have any health problems between check-ups, call your doctor.

Your oncology doctor will make a follow-up plan which may include: physical exams, blood tests, urine tests, cystoscopy, CT scans, along with cytology/urethra wash, and chest x-ray.

On the next page we've given you space to write down any question you may have for your healthcare team regarding your treatment options and recovery.

Notes

Questions

Answers

University of Michigan Rogel Cancer Center Resources

Bladder cancer support group



The University of Michigan Bladder Cancer Support Group is the only group in the state of Michigan specific to bladder cancer and one of a few across the country. This group has been used as the benchmark for newly founded groups across the country. A support group is a gathering of people who share a common health concern or interest.

Patient and family support, reassurance, education and guidance are key for treatment recovery and long term quality of life. This was realized by one of Dr. Montie's first neobladder patients. He founded the first Bladder Cancer Support Group at the University of Michigan about 15 years ago.

Today, the Bladder Cancer Support Group is thriving with nearly 40-80 attendees at most meetings. The group meets every other month on a Sunday. The group:

- Acts as a forum for patients and families to lend support, strength, and ideas to each other.
- Promotes bladder cancer awareness.
- Adds to the understanding of the disease and its treatment.
- Gives optimal coping methods for patients and families.
- Informs patients and families about ongoing research.

The benefit of the bladder cancer support group has been impressive. The group has been involved in advocacy, getting better education to those diagnosed with bladder cancer, and being mentors to those newly diagnosed with bladder cancer. The Bladder Cancer Support Group has started a "Buddy List." This is a list of patient volunteers and their families who have agreed to talk to others. This list includes their contact information, type of bladder cancer treatment, and their doctor.

In earlier times, barn raisings, square dances, quilting bees, and other community gatherings were places folks came together to celebrate, nurture, encourage, and comfort one another. Today, we still need to be nurtured, comforted, and encouraged during hard times. The Bladder Cancer Support Group brings people together facing like issues and gives a place to share their story.

Please call 734-615-6662 for information on The Bladder Cancer Support Group.

The Practical Assistance Center (PAC)

When patients need help that goes beyond what the University of Michigan Health System can give, the Center helps find resources to meet patients' needs. Patients may qualify for assistance from cancer-specific organizations or other charitable foundations.

Resources may be available to qualified patients for:

- Lodging
- Meals
- Parking
- Prescriptions
- Transportation
- Wigs
- Other unforeseen needs

The PAC also helps connect patients to resources within the U-M Health System, such as:

- Clinic social workers.
- Financial Services, which handle billing concerns and payment programs.
- Patient & Visitor Accommodations, which helps families find lodging in the Ann Arbor area.

You can contact the PAC by calling 877-907-0859; or visit the Center on level 1 of the Rogel Cancer Center.

Cancer Resources

American Bladder Cancer Support

www.bladdercancersupport.org

American Cancer Society

1-800-ACS-2435

www.cancer.org

American Society for Clinical Oncology

888-651-3038

www.cancer.net

American Urological Association Foundation

866-746-4282

www.auafoundation.org

Bladder Cancer Advocacy Network (BCAN)

888-901-BCAN

www.bcan.org

Bladder Cancer Webcafe

www.blcwebcafe.org

CancerCare

800-813-HOPE

www.cancercare.org

Lance Armstrong Foundation

866-467-7205

www.livestrong.org

National Cancer Institute

888-4-CANCER

www.cancer.gov

National Comprehensive Cancer Network (NCCN)

215-690-0300

www.nccn.org

United Ostomy Associations of America, Inc.

800-826-0826

www.uoaa.org

The Wellness Community

888-793-WELL

www.thewellnesscommunity.org

University of Michigan Rogel Cancer Center

<http://www.rogelcancercenter.org/bladder-cancer>

University of Michigan Rogel Cancer Center

www.rogelcancercenter.org/patients

Words to know

This is a list of words that you may find throughout the handbook.

- **Abdomen:** the part of the body that contains the pancreas, stomach, intestines, liver, gallbladder, and other organs.
- **Adenocarcinoma:** Cancer that begins in cells that line certain internal organs and that have gland-like (secretory) properties.
- **Adjuvant:** Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.
- **Anesthesia:** loss of feeling or awareness. Local anesthetics cause loss of feeling in a part of the body. General anesthetics put the person to sleep.
- **Arsenic:** a poisonous chemical used to kill weeds and pests. Also used in cancer therapy.
- **Bacteria:** a large group of single-cell microorganisms. Some cause infections and disease in animals and humans. The singular of bacteria is bacterium.
- **BCG solution:** a form of biological therapy for non-muscle invasive bladder cancer. A catheter is used to place the BCG solution into the bladder. The solution contains live, weakened bacteria (Bacille Calmette-Guerin) that activate the immune system. The BCG solution used for bladder cancer is not the same thing as BCG vaccine, a vaccine for tuberculosis.
- **Benign:** not cancerous; does not invade nearby tissue or spread to other parts of the body.
- **Biological therapy:** treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also used to lessen side effects that may be caused by some cancer treatments. Also known as immunotherapy, biotherapy, or biological response modifier (BRM) therapy.
- **Biopsy:** the removal of cells or tissues for examination under a microscope. When only a sample of tissue is removed, the procedure is called an incisional biopsy or core biopsy. When an entire tumor or lesion is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle aspiration.

- **Bladder:** the organ that stores urine.
- **Bladder cancer:** Cancer that forms in tissues of the bladder (the organ that stores urine). Most bladder cancers are transitional cell carcinomas (cancer that begins in cells that normally make up the inner lining of the bladder). Other types include squamous cell carcinoma (cancer that begins in thin, flat cells) and adenocarcinoma (cancer that begins in cells that make and release mucus and other fluids). The cells that form squamous cell carcinoma and adenocarcinoma develop in the inner lining of the bladder as a result of chronic irritation and inflammation.
- **Bone scan:** a technique to create images of bones on a computer screen or on film. A small amount of radioactive material is injected into a blood vessel and travels through the bloodstream; it collects in the bones and is detected by a scanner.
- **Cancer:** a term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.
- **Carcinoma in situ:** Cancer that involves only the cells in which it began and that has not spread to neighboring tissues.
- **Chemotherapy:** treatment with anticancer drugs.
- **Clinical trial:** a research study that tests how well new medical treatments or other interventions work in people. Each study is designed to test new methods of screening, prevention, diagnosis, or treatment of a disease.
- **CT scan:** Computed tomography scan. A series of detailed pictures of areas inside the body taken from different angles; the pictures are created by a computer linked to an x-ray machine. Also called computerized tomography and computerized axial tomography (CAT) scan.
- **Cystectomy:** surgery to remove all or part of the bladder.
- **Cystoscope:** a thin, lighted instrument used to look inside the bladder and remove tissue samples or small tumors.
- **Cystoscopy:** examination of the bladder and urethra using a thin, lighted instrument (called a cystoscope) inserted into the urethra. Tissue samples can be removed and examined under a microscope to determine whether disease is present.

- **Enterostomal therapist:** a health professional trained in the care of persons with urostomies and other stomas.
- **External radiation:** radiation therapy that uses a machine to aim high-energy rays at the cancer. Also called external-beam radiation.
- **Gene:** the functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.
- **Grade:** the grade of a tumor depends on how abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. Grading systems are different for each type of cancer.
- **Ileal conduit:** a simple form of urinary tract reconstruction which utilizes a small piece of intestine called the ileum. The ureters are implanted into this small segment of intestine, one end is closed with sutures, and the other is brought out to the skin to create a small opening, or mouth, called a stoma. Urine drains into a small pouch that fits over the stoma and attaches to the skin with an adhesive.
- **Imaging:** tests that produce pictures of areas inside the body.
- **Immune system:** the complex group of organs and cells that defends the body against infection or disease.
- **Impotent:** Unable to have an erection adequate for sexual intercourse.
- **Intravenous:** IV. Into a vein.
- **Intravenous pyelogram:** IVP. A series of x-rays of the kidneys, ureters, and bladder. The x-rays are taken after a dye is injected into a blood vessel. The dye is concentrated in the urine, which outlines the kidneys, ureters, and bladder on the x-rays.
- **Intravesical:** within the bladder.
- **Invasive bladder cancer:** a bladder cancer that invades the structures that lie beneath the lining cells. These tumors have characteristically bad biological behavior and are capable of spreading to other parts of the body without much warning. Accordingly, physicians are constantly on the lookout for evidence of disease spread in patients with invasive bladder carcinomas. Invasive cancers are less common than superficial ones, but they unfortunately spread to other parts of the body in about half of the patients who have this invasive disease.

- **Invasive cancer:** cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues. Also called infiltrating cancer.
- **Kidneys:** A pair of organs in the abdomen that remove waste from the blood (as urine), produce erythropoietin (a substance that stimulates red blood cell production), and play a role in blood pressure regulation.
- **Lamina propria:** a specialized layer of blood vessels and cells that separates the transitional epithelium from the actual muscle wall of the bladder.
- **Local therapy:** treatment that affects cells in the tumor and the area close to it.
- **Lymph node:** a rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Also known as a lymph gland. Lymph nodes are spread out along lymphatic vessels and contain many lymphocytes, which filter the lymphatic fluid (lymph).
- **Lymphatic system:** the tissues and organs that produce, store, and carry white blood cells that fight infection and other diseases. This system includes the bone marrow, spleen, thymus, lymph nodes, and network of thin tubes that carry lymph and white blood cells. These tubes branch, like blood vessels, into all the tissues of the body.
- **Magnetic resonance imaging:** MRI. A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.
- **Malignant:** cancerous; a growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body.
- **Medical oncologist:** a doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often serves as the main caretaker of someone who has cancer and coordinates treatment provided by other specialists.
- **Metastasis:** the spread of cancer from one part of the body to another. Tumors formed from cells that have spread are called “secondary tumors” and contain cells that are like those in the original (primary) tumor. The plural is metastases.
- **Metastasize:** to spread from one part of the body to another. When cancer cells metastasize and form secondary tumors, the cells in the metastatic tumor are like those in the original (primary) tumor.

- **Neoadjuvant therapy:** Treatment given as a first step to shrink a tumor before the main treatment, which is usually surgery, is given. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and hormone therapy. It is a type of induction therapy.
- **Neobladder:** a new bladder usually constructed out of a piece of intestine and attached to the urethra. This is placed in the position that had been occupied by the bladder before it was removed because of disease.
- **Ostomy:** An operation to create an opening (a stoma) from an area inside the body to the outside. Colostomy and urostomy are types of ostomies.
- **Ovaries:** the pair of female reproductive glands in which the ova, or eggs, are formed. The ovaries are located in the pelvis, one on each side of the uterus.
- **P53:** a particularly notable tumor-suppressor gene that is thought to play a central role in normal cells' growth regulation. Mutation of the P53 tumor suppressor gene has been shown to occur in up to 40 percent of invasive bladder carcinomas. Some scientists believe that P53 mutation may be a marker of the presence of a dangerous type of tumor which could require multiple therapies to cure.
- **Pathologist:** a doctor who identifies diseases by studying cells and tissues under a microscope.
- **Pelvis:** the lower part of the abdomen, located between the hip bones.
- **Primary tumor:** the original tumor.
- **Prostate:** a gland in the male reproductive system just below the bladder. It surrounds part of the urethra, the canal that empties the bladder, and produces a fluid that forms part of semen.
- **Radiation oncologist:** a doctor who specializes in using radiation to treat cancer.
- **Radiation therapy:** the use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body in the area near cancer cells (internal radiation therapy, implant radiation, or brachytherapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy.

- **Radical cystectomy:** surgery to remove the bladder as well as nearby tissues and organs.
- **Radioactive:** giving off radiation.
- **Rectal:** by or having to do with the rectum. The rectum is the last 8-10 inches of the large intestine and ends at the anus.
- **Recur:** to occur again. Recurrence is the return of cancer, at the same site as the original (primary) tumor or in another location, after the tumor had disappeared.
- **Refractory:** In medicine, describes a disease or condition that does not respond to treatment.
- **Risk factor:** a habit, trait, condition, or genetic alteration that increases a person's chance of developing a disease.
- **Segmental cystectomy:** the removal of the cancer as well as some of the bladder tissue around the tumor. Sometimes called a partial cystectomy.
- **Side effects:** problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.
- **Small intestine:** the part of the digestive tract that is located between the stomach and the large intestine.
- **Sonogram:** a computer picture of areas inside the body created by bouncing sound waves off organs and other tissues. Also called ultra-sonogram or ultrasound.
- **Sphincter muscle:** a specialized circular muscle that effectively cuts off the flow of urine when contracted. Men have two such sphincter mechanisms, one at the junction of the prostate and bladder and the other just below the prostate in the upper part of the urethra. The second sphincter, which wraps around the urethra, is the one that is thought to be responsible for continence in females.
- **Squamous cell carcinoma:** cancer that begins in squamous cells, which are thin, flat cells resembling fish scales. Squamous cells are found in the tissue that forms the surface of the skin, the lining of the hollow organs of the body, and the passages of the respiratory and digestive tracts. Also call epidermoid carcinoma.

- **Squamous cells:** flat cells that look like fish scales under a microscope. These cells cover internal and external surfaces of the body.
- **Stage:** the extent of a cancer, especially whether the disease has spread from the original site to other parts of the body.
- **Staging:** performing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body.
- **Stoma:** a surgically created opening from an area inside the body to the outside.
- **Superficial:** affecting cells on the surface. Not invasive.
- **Superficial bladder cancer:** tumors arising from the lining of the bladder that do not invade the lamina propria or muscle wall. The majority of bladder cancers are superficial, and, though these progress in only a minority of patients, they do usually recur.
- **Surgeon:** A doctor who removes or repairs a part of the body by operating on the patient.
- **Surgery:** A procedure to remove or repair a part of the body or to find out whether disease is present.
- **Symptom:** an indication that a person has a condition or disease. Some examples of symptoms and headache, fever, fatigue, nausea, vomiting, and pain.
- **Systemic therapy:** treatment that uses substances that travels through the bloodstream, reaching and affecting cells all over the body.
- **Tissue:** a group or layer of cells that are alike in type and work together to perform a specific function.
- **Transitional cell carcinoma:** a type of cancer that develops in the lining of the bladder, ureter, or renal pelvis. Also referred to as urothelial cell carcinoma.
- **Transitional cells:** cells that vary in shape depending on whether the tissue is being stretched. The cells may be stretched without breaking apart. They line hollow organs such as the bladder.
- **Transurethral resection:** surgery performed with a special instrument inserted through the urethra. Also called a TUR.

- **Trigone:** the floor of the bladder, where the ureters and urethra connect to the interior of the bladder.
- **Tumor:** an abnormal mass of tissue that results from excessive cell division. Tumors perform no useful body function. They may be benign (not cancerous) or malignant (cancerous).
- **Ureter:** the tube that carries urine from the kidney to the bladder.
- **Urethra:** the tube through which urine leaves the body. It empties urine from the bladder.
- **Urine:** fluid containing water and waste products. Urine is made by the kidneys, stored in the bladder, and leaves the body through the urethra.
- **Urologic oncologist:** a doctor who specializes in treating cancers of the urinary system.
- **Urologist:** a doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs in males.
- **Urostomy:** an operation to create an opening from inside the body to the outside, making a new way to pass urine.
- **Uterus:** the small, hollow, pear-shaped organ in a woman's pelvis. This is the organ in which a fetus develops. Also called the womb.
- **Vagina:** the muscular canal extending from the uterus to the exterior of the body. Also called the birth canal.
- **Vaginal:** of or having to do with the vagina, the birth canal.
- **Wound, Ostomy and Continence Nurse:** A registered nurse who has additional education and training in how to care for people who have a wound, an ostomy (an opening made by surgery, from an area inside the body to the outside), or problems with continence (ability to control the flow of urine or the passage of stool). Also called WOC nurse.
- **X-ray:** high-energy radiation used in low doses to diagnose diseases and in high doses to treat cancer.

Notes

Questions

Answers

Faculty and staff of these programs supplied facts for this handbook: Ambulatory Care Ostomy Nursing Services, Cancer Patient Education, HomeMed®Nursing, Medical Urology Oncology, Urology Oncology Nursing

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