

Testicular Cancer Patient Guide



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Mike's Story



In 2005, Mike was 33 years old and living in South Florida when he felt a lump on his left testicle. He knew right away that something wasn't right. He said to himself, "this is cancer and I'm going to die soon."

Rather than going to the doctor, Mike decided to live large. He threw himself a "good bye" party to see everyone he cared about. He jumped at every chance to take advantage of life – like skiing, partying and traveling. But the outside persona he adopted didn't tell the full story. Inside, Mike was "living a mental nightmare." He was scared, sad and acting erratically.

Finally, after seven months, Mike went to his primary care doctor, who sent him to a urologist to confirm he had testicular cancer. He was told he was very lucky, because his cancer was still a stage I seminoma. It hadn't yet spread to his lymph nodes.

Mike's urologist offered him three choices for treatment: radiation therapy, chemotherapy or the lesser-known option (at the time) of active surveillance. He was asked what he wanted to do. Because Mike is a pharmacist, he was invested in doing his own research to figure out what was best for him. Mike chose active surveillance. This saved him from dealing with side effects for five years.

Mike knew he would eventually need testicular cancer surgery – a 45-minute procedure to remove the cancerous testicle from his groin. For five years he chose active surveillance with CT scans, chest x-rays and tumor marker blood tests.

Now, 13 years later, Mike says if he could turn back time, he would have skipped the mental distress he felt in the beginning before he went to the doctor. Mike wishes he could give a little advice to all men, such as:

"If you know something is wrong, don't wait – go to the doctor!" If it's nothing, the doctor won't think badly of you. If it's something, you can treat this cancer before it spreads.

"Make sure you advocate for yourself." It's easier for men to help others and they don't always think to help themselves. This is not the time for that. Be patient and do your own research to learn everything you can.

Now Mike is the founder of the Testicular Cancer Society, a non-profit organization dedicated to increasing awareness and education about testicular cancer to support fighters, survivors and caregivers. While about 60 percent of the calls to his group are from the women in men's lives, he hopes to see more men taking an active role to reach their goal of being cancer-free.

Introduction

While testicular cancer can affect a boy or man at any age (from newborn to elderly), it's most often found in men between the ages 15 to 44 years old. It's always a shock to learn cancer has grown in the testis, especially at a young age. However, with early diagnosis, this cancer can be treated and even cured. It's vital not to wait.

The most common care includes surgery, sometimes followed by radiation and/or chemotherapy. These treatments can cure almost 100 percent of early tumors and 85 percent of more advanced tumors. How well a patient reacts to treatment depends on the type of cancer cell, whether it has spread and the patient's overall health.

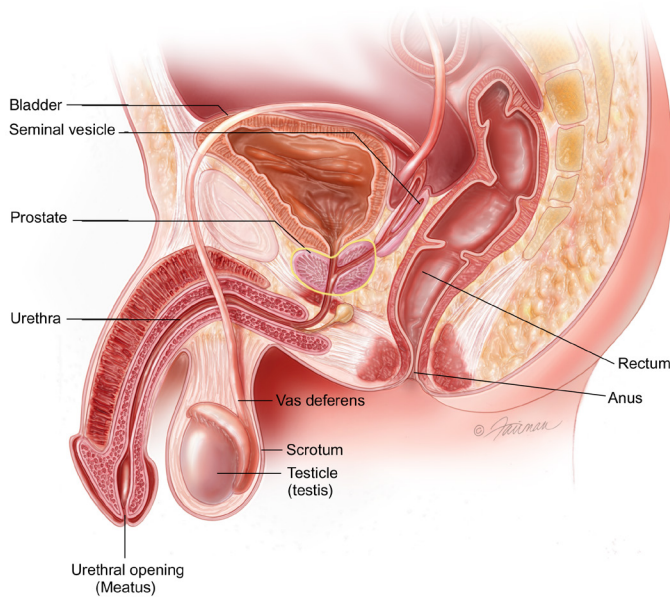
If testicular cancer spreads beyond the testis, it is harder to treat.

The Urology Care Foundation's goal is to help men learn about the signs, symptoms and treatments for testicular cancer. This patient guide is designed to share what you need to know about testicular cancer. We explain how it's found, how to do a testicular self-exam and what you should know about treatment. These facts can arm you with the tools you'll need to tackle this disease.

How Do Testicles Work?

The male reproductive organs include internal and external parts. The main reproductive organs are the penis, scrotum with testicles and prostate.

Male Anatomy



These male organs are designed to:

- Make and release male sex hormones for growth of muscle, bone and body hair
- Make and move **sperm** for reproduction, and fluid to protect it (**semen**)
- Carry sperm into the female reproductive tract

The testicles are two small egg-shaped glands, held in a sac below the penis (the scrotum). This is where sperm form and mature. From there, sperm moves into the vas deferens (a “tube” behind the testicles) and out the **urethra** when ejaculated. The testicles also make male hormones like testosterone. Testosterone controls the sex drive in men and starts the growth of muscle, bone and body hair.

Healthy testicles have a firm, slightly spongy feel. The firmness should be the same throughout. The size of both testicles should be about the same, though one may be larger than the other.

What is Testicular Cancer?

Testicular cancer happens when cells in the testicle grow to form a **tumor**. This is rare. More than 90 percent of testicular cancers begin in the germ cells, which produce sperm. There are two types of germ cell cancers (GCTs). Seminoma can grow slowly and respond very well to **radiation** and **chemotherapy**. Non-seminoma can grow more quickly and can be less responsive to those treatments. There are a few types of non-seminomas: choriocarcinoma, embryonal carcinoma, teratoma and yolk sac tumors.

There are also rare testicular cancers that don’t form in the germ cells. Leydig cell tumors form from the Leydig cells that produce testosterone. Sertoli cell tumors arise from the Sertoli cells that support normal sperm growth.

Testicular tumors can be made of more than one type of cell.

The type of testicular cancer cell found, symptoms and other factors will help guide your treatment.

What are the Symptoms of Testicular Cancer?

The symptoms of testicular cancer may be hard to notice, especially at first. Symptoms of a testicular tumor include:

- A painless lump in the testicle, which is the most common sign
- Swelling of the testicle, with or without pain
- A feeling of weight in the testicles
- A dull ache or pain in the testicle, scrotum or groin
- Tenderness or changes in the male breast **tissue**

If you find any lump or firm part of the testicle, you should see a doctor to find out if it is a tumor. It should be tested as soon as possible. About 75 out of 100 men with swelling or a lump in the testicle have cancer. Most masses in the scrotum outside of the testicle, are not cancer. No matter what, if you find a lump, tell your doctor.

On average, most men don’t tell anyone about signs or symptoms like these. They instead wait for five or more months before saying anything.

If you wait, the cancer can spread. It’s of great value to talk with your doctor or **urologist** if you find a lump that lasts longer than two weeks. The urologist will want to test if cancer is growing or if there’s some other issue, like:

** All words that appear in blue Italics are explained in the glossary.*

- **Epididymitis:** swelling of the epididymis. Often treated with antibiotics.
- **Testicular torsion:** twisting of the testicles. Often treated with surgery.
- **Inguinal hernia:** when part of the intestine pokes through a weak part of the stomach muscles near the groin. Often treated with surgery.
- **Hydrocele:** when fluid builds up in the scrotum. This is not dangerous but can be treated with surgery if bothersome.

What Causes Testicular Cancer?

It is not always known why cells grow to form a tumor. Also, you may not be able to avoid the risk factors of testicular cancer. The best plan is to catch this problem early.

Who Gets Testicular Cancer?

The risk for getting testicular cancer rises for men with:

- **Family history:** If your father or brother had testicular cancer.
- **Undescended testicles:** If your testicles did not drop before birth. This can also be called cryptorchidism and is when a testicle did not drop from the abdomen into the scrotum before birth, as it should. A tumor is more likely to grow after this issue. Surgery can fix the testis, but cancer can still develop. About 8 out of 100 of these patients get cancer.
- **GCNIS:** These are odd cells in the testicle called germ cell neoplasia in situ (GCNIS) and they are typically found during an infertility test.

Microlithiasis, or small calcifications in the testicle, is not a risk factor for testicular cancer (unless you have one of the risk factors above).

GET DIAGNOSED

Understanding how testicular cancer could affect you starts with a conversation. Your doctor will ask you questions about your general health and talk about your concerns. Many men are able to identify a problem with their testicles by doing a self-exam. Testicular cancer is one of the most treatable cancers. When caught early, the cure rate is close to 100 percent. This is true for men with early stage testicular cancer, where it has not spread past the testicle. For men with stage II or III testicular cancer, the cure rate is still higher than other cancers. If you notice a lump, or feel discomfort, swelling, pain or other changes in your testicles or scrotum, see a doctor. Ideally, you can meet with a urologist.

Testicular Self-Exam

The best time to do a monthly testicular self-exam is after a warm bath or shower, while standing, when the scrotum is relaxed. It only takes a few minutes. To start:

- 1) **Check each testicle.** Gently but firmly roll each testicle between the thumb and forefingers. Feel the whole surface. The firmness of the testis should be the same all around. It's normal for one testis to be slightly larger than the other.
- 2) **Find the epididymis and vas deferens.** These are soft tube-like structures above and behind the testicle. These

tubes collect and carry sperm. Just become familiar with how these cords feel.

- 3) **Look for lumps, swelling or things that don't seem right.** Lumps or bumps are not normal (even if they cause no pain). Pain is not normal.
- 4) **Check yourself at least once per month.** Always look for changes in size, shape or texture. If you notice a lump or any changes over time, you should seek medical help. It may be nothing, but if it is testicular cancer, it can spread very quickly. When found early, testicular cancer is curable. If you have any questions or concerns, talk to your urologist.

Medical Exams

Your doctor will talk with you about your symptoms, your overall health and will do a medical exam. If the doctor suspects something is not normal, they will run more tests.

HEALTH RECORD AND PHYSICAL EXAM

Your urologist will talk with you about your health. They'll examine your scrotum, belly, **lymph nodes** and other parts to look for signs of cancer. They'll look for lumps, firmness or signs of swelling. Tell them if you have a history of undescended testicles.

TESTICULAR ULTRASOUND

This imaging test is used to see inside the scrotum and check a suspicious lump. Other scans or x-rays may be done if your doctor would like to see inside your chest or abdomen. This is done to see if cancer has spread to lymph nodes, the lungs or liver. MRIs are rarely used, but in some cases are needed to check the brain and spinal cord.

BLOOD TEST

A blood test is taken to check tumor markers. These are proteins and hormones made by some testicular cancers. AFP, ACG and LDH tumor markers rise with some cancers but many testicular cancers will not produce tumor markers. In other words, just because tumor markers are normal does not mean you are free of cancer. It's of great value to ask your doctor about your tumor marker levels and learn what's normal vs. not normal.

SERUM TUMOR MARKER TEST

Tumor markers (AFP, HCG, and LDH) should be measured before any treatment, such as surgery. If cancer is found, tumor marker tests will be repeated after treatment to track how well you're doing over time. Some medicines and marijuana can create false positive levels of HCG. Tell your doctor about your medicine and/or marijuana use. It is also worth noting that:

- Pure seminomas can raise HCG levels but never AFP levels
- Non-seminomas often raise AFP and/or HCG levels
- Over the counter urinary pregnancy tests do check for HCG levels in the **urine** but are not reliable tests for testicular cancer

Staging

If your urologist finds cancer through these exams, they will want to learn the exact cancer cell-type and if it has spread. This is called staging. This process helps the doctor learn which treatments are best.

Testicular cancer is not found with a standard **biopsy** (tissue sample). With this cancer, cells are examined after the cancerous tissue is removed in surgery.

Testicular Cancer is grouped into the following stages:

Stage 0: This is also called "Germ Cell Neoplasia In Situ (GCNIS)". This is not yet cancer, but a warning that cancer could grow. GCNIS may be found in the seminal tubules and nowhere else.

Stage I (IA, IB, IS): Cancer is found only in the testicle. It has not spread to nearby lymph nodes or anywhere else in the body.

Stage II (IIA, IIB, IIC): Cancer has spread to one or more lymph nodes in the belly (often the first site of testicular cancer spread). It has not spread to other parts of the body.

Stage III (IIIA, IIIB, IIIC): Cancer has spread beyond the lymph nodes in the belly. Cancer may be found far away from the testicles, such as distant lymph nodes or the lungs. Tumor marker levels are high.

GET TREATED

Often, a team of doctors, such as a urologist, **oncologist** or a radiation oncologist, will work together to find the best plan to treat each patient. Choices will be based on the exact diagnosis and health of the patient.

Before treatment, men should talk with their urologist about whether or not they want to have children. Not being able to have children and changes in male hormones are common after certain treatments. Sperm banking may be useful before treatment, especially if you hope to have children in the future.

Men can also ask about a **testicular prosthesis** before surgery. This is a way to make the scrotum look more "normal" after a testis is removed.

Surveillance

Surveillance is a way to look for changes with normal checkups. These include a physical exam, tumor marker tests and imaging tests. Imaging tests start with an **ultrasound** of the scrotum. They can also involve chest x-rays or CT scans. Most men may be checked for signs of low testosterone as well.

Surveillance is recommended for patients with Stage 0 and some Stage I cancers as described below.

Stage I seminoma. Surveillance is one option for stage I seminoma after surgery. It should involve a physical exam and imaging and may include tumor markers. It is generally every six months for the first two years and then every six to 12 months in years three through five. Surveillance may

be less frequent for stage I cancers treated with adjuvant chemotherapy or radiation.

Stage I non-seminoma germ cell tumors (NSGCT).

Surveillance is one option for stage I NSGCT after surgery. It should include a physical exam, imaging and tumor marker test. The timing may be every two months during the first year; every three months in year two; every four to six months in year three and every six to 12 months in years four through five. This timing may be more frequent for patients with additional risk factors.

Standard surveillance by cell-type. This surveillance can be broken down into two categories:

- **Seminoma – Active surveillance** is often used after initial orchiectomy for low stage seminomas. In later stages, this cancer is often treated successfully with surgery, radiation and chemotherapy.
- **Non-seminomas** – Treatment for this type of cancer may involve surveillance after initial orchiectomy for low stages. Later stages may be treated with chemotherapy or surgery. The treatment used depends on the exact diagnosis and whether the disease has spread.

If the cancer shows signs of growth, or if hormone levels change, then more treatment may be offered.

Surgery

Surgery is the main treatment for testicular cancer. Based on the diagnosis, other choices may be offered. Changes in fertility should be discussed before surgery.

ORCHIECTOMY

Orchiectomy is used to diagnose and treat early-stage or later-stage cancer. This surgery removes the entire testicle and mass through a small cut in the groin. The spermatic cord is also removed. A **pathologist** will stage the cell type after surgery.

Routine surveillance is done after surgery to make sure the cancer doesn't return. If one testicle is removed and the other is normal, testosterone levels should be fine. The remaining testicle should make enough testosterone. Also, if a man is worried about the way he looks, a testicular prosthesis (fake testicle) is an option.

TESTIS SPARING SURGERY

Testis-sparing surgery (TSS) is sometimes recommended for some men. This surgery removes just the tumor tissue, not the entire testis. For TSS, the mass must be very small

and tumor markers must be negative. TSS is best for men who have benign tumors rather than cancer. If the tumor is cancerous and the patient has a normal testicle on the other side, TSS is not recommended.

Surveillance after surgery is important to check for cancer.

RETROPERITONEAL LYMPH NODE DISSECTION

Retroperitoneal lymph node dissection (RPLND) is a complex surgery, helpful for some men. It needs a skilled surgeon to remove lymph nodes in the back of the abdomen to ensure limited side effects. This surgery is an option for patients with a more forceful Stage I cancer. It is typically used for men with non-seminomatous germ cell tumors that may return. It can be used rather than chemotherapy for stage IIA or IIB non-seminoma tumors. After RPLND surgery, either chemotherapy or surveillance is offered based on the cancer location, type and the risk that it can return.

Radiation

Radiation is used to kill cancer cells in the testis or in nearby lymph nodes. It is only used in seminoma because some forms of non-seminoma are resistant to radiotherapy. It may be an option if testicular cancer (either type) has spread to far organs like the brain. There are a few radiation therapy types used.

Chemotherapy

Chemotherapy is used for cancers that spread beyond the testicles, or if tumor markers rise after surgery. Serum tumor markers and imaging tests help guide how much chemotherapy to use, and if it can help.

These drugs travel around the body through the bloodstream and may cause side effects. They can wipe out cancer cells that may have traveled to lymph nodes. Chemotherapy is also used to help lower the risk of cancer coming back after surgery.

One, two or three chemotherapies may be combined for testicular cancer treatment. These drugs are given in three or four three-week cycles. Sometimes more surgery will be done to remove tumors after chemotherapy is complete.

Further Treatment

Beyond basic surgery, care depends on the type of cell and follow-up tests. Even if cancer was found early and treated, follow-up tests are recommended. If, after time, cancer returns, then more treatment will be needed.

CHILDREN WITH TESTICULAR CANCER

Testicular tumors in children are rare. If they are found early, treatment is often successful. If a tumor is found after it has spread, it's harder to treat. As with men, this cancer often begins as a painless lump.

Get Children Diagnosed

The most common type in boys are yolk sac tumors and teratomas. The cancer cell-types found in children are:

- **Yolk Sac Tumors.** These are often treated successfully and are rare in adults.
- **Teratomas.** These germ cells grow in hard-to-predict ways and do not respond to chemotherapy. They can be treated with surgery.
- **Gonadal Stromal Tumors.** These are more likely to spread and require a chest x-ray if found.
- **Gonadoblastoma and Dysgerminoma.** These are rare and they happen in children with testicles that did not grow normally before birth.
- **Gonadoblastomas.** These cells are benign and they can become cancer in 50 percent of cases.

Treatment for Children

The most common treatments for children with testicular tumors are:

- **Inguinal Exploration.** For this surgery, a cut on the skin crease just above the pubic bone is made and the testicle is guided out of the scrotum. The surgeon then looks at the gland to decide next steps. This is recommended for any child with a testicular tumor. It is most often an outpatient service.
- **Testis Sparing Surgery (TSS).** This is a choice when the surgeon thinks the tumor is benign. A surgeon decides on TSS based on how the tumor looks and on normal tumor markers. In this case, just the tumor tissue is removed (biopsy) and sent to a pathologist for testing.
- **Total Orchiectomy.** Surgery to remove the testis is needed if biopsy results show cancer. This may be recommended in patients with large tumors, high tumor markers or those whose tumors are found after puberty.
- **Further treatment** is offered if the cancer is more aggressive. These options include a RPLND, radiation or chemotherapy.

Children after Treatment

After treatment, children are checked for at least two years to make sure all is well. Physical exams, tumor marker tests and chest x-rays are common follow-up tests. Most often boys do not look different if a testicle is removed. The scrotum is not cut and the other testicle keeps growing. If a boy does not like the result, a prosthesis is an option. This is most often done after puberty.

Most boys who've been treated for testicular cancer will be healthy and can have children when they grow up.

OTHER CONSIDERATIONS

Risk for Return

The risk of testicular cancer coming back depends on the stage at diagnosis, but it's very small, at 5 percent or less. There is also a very small (about 2 percent) risk of cancer growing in the other testicle. Still, it is of great value to learn how to do a testicular self-exam. Also, regular follow-up visits with your urologist will be important. How often, and for how long follow-up care is needed is based on your diagnosis.

If cancer returns, the doctor will want to find it and treat it quickly. Additional treatment depends on the cancer type and location. RPLND surgery, radiation and chemotherapy are options.

Sex Life and Fertility

The removal of one testicle should not change your sexual energy or fertility (chances of having a child). Most men can have a normal erection after surgery. Still, men diagnosed with testicular cancer have a higher risk of infertility and low testosterone. You may also have a decrease in sperm growth after chemotherapy or radiation that will usually recover. If lymph nodes were removed, it may be harder to ejaculate. If you have problems, there are treatments that can help with **ejaculation**. If you are worried, talk with your doctor.

As you heal, your body will find balance. Over time, the healthy testicle will usually make enough testosterone to help you return to normal. Your doctor may check hormone levels on an annual basis as part of your check-up.

Treatment Risk

Patients who've had radiation and/or chemotherapy should pay attention to their heart health. Their risk for cardiovascular disease rises after treatment. Simple lifestyle changes can prevent problems. For example, strive to exercise regularly, eat less processed food and stop smoking/vaping. Be sure to ask for regular check-ups to test your blood pressure, lipid and glucose levels.

Patients who've had radiation and/or chemotherapy may be at higher risk of developing different cancer in the future. You should make sure you follow with a primary care physician to ensure you get appropriate screening.

Testosterone levels in men treated for testicular cancer can also be lower. Patients should be watched for signs and symptoms of lower testosterone and can be checked with a blood test if symptoms develop.

Questions to Ask Your Doctor

Diagnosis Questions

- Can you explain the type of testicular cancer I have – is it aggressive?
- Is the cancer only in my testicle or could it have spread to other areas? If so, where?
- Do I need any other tests?
- Can you recommend a specialist?

Treatment Questions

- Can you explain my treatment options?
- Where do I go for treatment? Should I see a radiologist or oncologist?
- What are the pros and cons of each treatment?
- Can you explain the risks or side effects of each treatment?
- If I need chemotherapy, what drug types are used and how do they work?
- How long will treatment take?
- Are side effects temporary or something that I'll need to manage over time?
- What should I expect as I recover from treatment?
- Does my insurance cover my treatment?
- I am interested in having children in the future; what should I do or know?

GLOSSARY

Abdomen

Also known as the belly. It is the part of the body that holds all of the organs between the chest and the pelvis.

Antidepressant

Medicine used to treat depression and related mental health problems.

Antihistamine

A drug that reverses the effects of histamine (a natural chemical that causes an allergic reaction).

Anxiety

Feelings of fear, dread and unease that happens as a reaction to stress.

Baseline Pain Value

A number value that represents how someone feels pain. Usually on a scale of 1 to 10 (10=extreme pain). It is used for comparison.

Biopsy

A procedure to take out small bits of tissue (cores) for testing.

Bladder

The hollow, balloon-shaped organ in which urine is stored before it moves through the urethra.

Bladder Infection

Also called a Urinary Tract Infection (UTI). This is an infection caused by bacteria that makes its way up your urethra and into your bladder. It can cause frequent urination and pain with urination.

Catheter

A thin tube that is inserted through the urethra into the bladder to allow urine to drain or for performance of a procedure or test, such as insertion of a substance during a bladder x-ray.

Cauterize

To burn an ulcer (sore) with heat or a chemical substance to destroy abnormal tissue.

Chronic Pelvic Pain

A collection of conditions that can include spasms, bladder and/or rectal pain.

Fibromyalgia

A condition of chronic pain in the muscles.

Irritable Bowel Syndrome

A chronic disorder that affects the large intestine (colon). It causes cramping, abdominal pain, bloating, gas, diarrhea and constipation.

Kegel Exercises

Exercises used to strengthen the muscles of the pelvic floor; often recommended to reduce incontinence and the symptoms of other urinary problems.

Kidneys

Two large, bean-shaped structures that remove waste from the blood.

Neuromodulation Therapy

A group of treatments that deliver harmless electrical impulses to nerves in order to change how they work.

Neurological Exam

An evaluation of a person's nervous system. This includes motor and sensory skills, balance and coordination, mental status, reflexes and nerve function.

Orgasm

A state of physical and emotional excitement. It occurs at the climax of sexual intercourse. In the male, it is linked to the ejaculation of semen.

Prostate

Is a walnut-sized gland in men. It is located below the bladder in front of the rectum. The prostate provides seminal fluid to the ejaculate.

Prostatitis

Inflammation or infection of the prostate. Chronic prostatitis means the prostate gets inflamed over and over again. Most common form is not from a bacteria or infecting organism.

Rectum

The lower part of the large intestine, ending in the anal opening.

Remission

A decrease in or disappearance of signs and symptoms of a disease or condition.

Urethra

A thin tube that carries urine from the bladder out of the body (in men, it also carries semen, and it exits through the end of the penis).

Urinary System

The body's system for removing waste and extra fluid from the body. The organs in the urinary system are the kidneys, ureters, bladder and urethra. For normal health, all parts of the system must work together in the correct order.

Urinary Tract Infection

Also called a Bladder Infection. This is an infection caused by bacteria that makes its way up your urethra and into your bladder. It can cause frequent urination and pain when passing urine.

Urine

A liquid, usually yellow in color, made by the kidneys and containing waste and water. Also known as pee.

Urodynamic Test

A series of tests that observe how well the urologic system collects, stores and releases urine.

Urologist

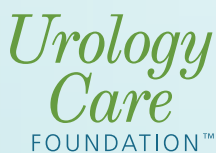
A doctor who specializes in the study, diagnosis and treatment of problems of the urinary tract.

About the Urology Care Foundation

The Urology Care Foundation is the world's leading urologic foundation – and the official foundation of the American Urological Association. We provide information for those actively managing their urologic health and those ready to make health changes. Our information is based on the American Urological Association resources and is reviewed by medical experts. To learn more, visit the Urology Care Foundation's website, **UrologyHealth.org/UrologicConditions** or go to **UrologyHealth.org/FindAUrologist** to find a doctor near you.

Disclaimer

This information is not a tool for self-diagnosis or a substitute for professional medical advice. It is not to be used or relied on for that purpose. Please talk to your urologist or healthcare provider about your health concerns. Always consult a health care provider before you start or stop any treatments, including medications. For more information, visit **UrologyHealth.org/Download** or call 800-828-7866.



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