

# 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. Luckily, Mike chose active surveillance. This saved him from dealing with side effects.

Eventually, he knew he needed to get testicular cancer surgery. That 45-minute procedure to remove his testicle from his groin was all he needed to be cancer-free. Mike's fears went away. For the next 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 and win 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 loyal 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 cancer cell-type, whether it has spread and the patient's overall health. If testicular cancer spreads beyond the testis, it is harder to treat.

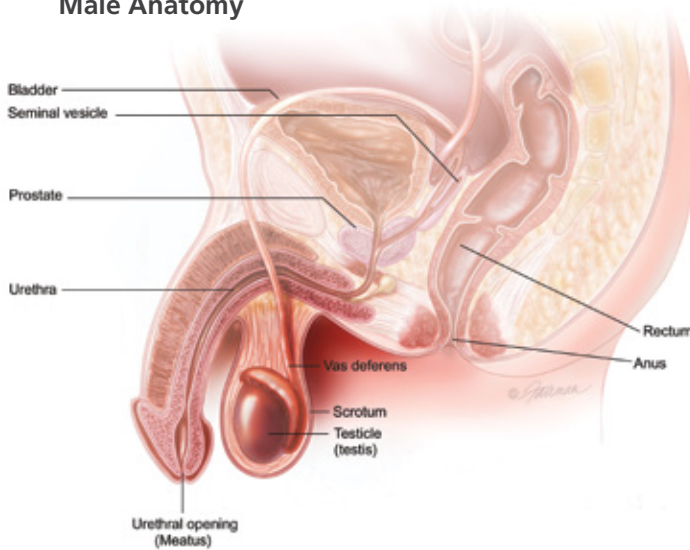
The Urology Care Foundation's goal is to help men learn about the signs, symptoms and treatments for testicular cancer. This patient guide is designed to share what you need to know about testicular cancer. We explain how it's found, how to do a testicular self-exam and what you should know about treatment.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

## GET THE FACTS

### 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 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, but outside of the testicle, are not cancer. No matter what, if you find a lump, tell your health care provider.

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.

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

If you wait, the cancer can spread. It's of great value to talk with your health care provider 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:

- **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 often goes away without treatment.

### 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).

Do a testicular self-exam each month. The self-exam can help you catch problems early, when treatment is easier.

## GET DIAGNOSED

Understanding how testicular cancer could affect you starts with a conversation. Your health care provider 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 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, he or she 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, a look at the cells is done after surgery to remove cancerous tissue.

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 check-ups. 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 should involve a physical exam, tumor marker test and imaging. It is generally every four to six months for the first two years, then every six to 12 months in years three through five.

**Stage I non-seminoma germ cell tumors (NSGCT).** Surveillance occurs after surgery. It should include a physical exam and tumor marker test. The timing may be every two to three months during the first year; every two to four months in year two; every four to six months in year three and every six to 12 months in years four through five.

**Stage I NSGCT.** Surveillance occurs after surgery. It should involve chest x-rays and other imaging. Timing of testing may be every four to six months in year one; every four to 12 months in year two and one time in years three through five.

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

- **Seminoma** -- **Active surveillance** is often used 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 and surgery. Later stages may be treated with chemotherapy. 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.

A 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 body part) 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 a man has a normal testicle on the other side, then 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 is 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 RLND, 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 important 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 brief decrease in sperm growth. If lymph nodes were removed, it may be harder to ejaculate. If you have problems, there are drugs 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 and lymph nodes will 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.

### Heart Disease 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 to stop smoking/vaping. Be sure to ask for regular check-ups to test your blood pressure, lipid and glucose levels.

### 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?

## GLOSSARY

### **ACTIVE SURVEILLANCE**

Watching testicular cancer with regular physical exams, blood tests and imaging tests on a set schedule. If symptoms begin or problems arise, more treatment will be offered

### **BIOPSY**

Removal of tissue samples for further testing. Samples are reviewed under a microscope and a pathologist can diagnose exactly which type of testicular cancer is found.

### **CHEMOTHERAPY**

The use of drugs to kill prostate cancer cells. This is only used with seminomas

### **EJACULATION**

The release of semen from the penis during sexual climax (ejaculate)

### **LYMPH NODES**

Rounded masses of tissue that make cells to fight germs or cancer

### **ONCOLOGIST**

A doctor who specializes in cancer treatment

### **PATHOLOGIST**

A doctor who identifies diseases by studying cells and tissues under a microscope

### **PENIS**

The male organ used for sex and to pass urine.

### **PROSTATE**

In men, a walnut-shaped gland below the bladder that surrounds the urethra and makes fluid for semen

### **RADIATION**

Use of radiation to treat testicular cancer (rays targeted at the tumor from outside the body)

### **SEMEN**

The fluid that protects and energizes sperm; also known as seminal fluid or ejaculate fluid

### **SPERM**

Male reproductive cells made in the testicles that can fertilize a female partner's eggs

### **TESTICLES**

Paired, egg-shaped glands located in a pouch (scrotum) below the penis. They produce sperm and the male hormone testosterone

### **TESTICULAR PROSTHESIS**

A prosthesis is an artificial device used to replace a body part. It is also called an implant. When a testicle must be removed due to cancer, a prosthesis can be inserted to fill the empty space in the scrotum

### **TISSUE**

Group of cells in an organism that is similar in form and function

### **TUMOR**

An abnormal mass of tissue or growth of cells

### **ULTRASOUND**

High-frequency sound waves used to create instant images of organs

### **URETHRA**

A narrow tube through which urine leaves the body. In males, semen travels through this tube during ejaculation. It extends from the bladder

### **URINE**

A liquid, usually yellow in color, made by the kidneys. It contains wastes and water.

### **UROLOGIST**

A medical doctor who specializes in urinary tract disorders and reproductive health.



## 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 healthy changes in their lives. Our information is based on the American Urological Association resources and is reviewed by medical experts.

To learn more about different urologic issues, visit **UrologyHealth.org/UrologicConditions**. 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 health care provider about your health concerns. Always consult a health care provider before you start or stop any treatments, including medications.

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For copies of other printed material and other urologic conditions, visit **UrologyHealth.org/Order**.

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