

# Non-metastatic Castration-Resistant Prostate Cancer (nmCRPC) Patient Guide



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## Introduction

Learning that you have non-metastatic castration-resistant prostate cancer (nmCRPC) may be alarming. It means that standard hormone therapy is not working to stop your cancer from growing. Give yourself time and space to take in what is happening. If you've been told you have nmCRPC, the good news is that your disease hasn't spread - it's not metastatic. There's a lot of helpful information and many people to support you through your next steps.

There are treatments for men with nmCRPC. Even though nmCRPC remains a serious disease and it must be managed

carefully, treatments may help delay disease progression.

This is your time to fight the battle against nmCRPC. There are many decisions to make throughout your prostate cancer journey but you are not alone. Your fight will involve a team with a urologist, oncologist and other health care providers, as well as your family and friends. Your treatment choices should be based on your personal health and age, and discussed fully with your team.

## GET THE FACTS

### How Does the Prostate Work?

The **prostate\* gland** is part of the male reproductive system. The prostate's main job is to make fluid for **semen**. It is about the size of a walnut and weighs an ounce or so. It sits below the **bladder** and in front of the **rectum**. It goes around a tube called the **urethra**. The urethra carries **urine** from the bladder and out through the **penis**.

During **ejaculation**, sperm made in the **testicles** moves to the urethra. While the sperm moves through the urethra, fluid from the prostate and the **seminal vesicles** joins in. This mixture—semen—goes through the urethra and out of the penis.

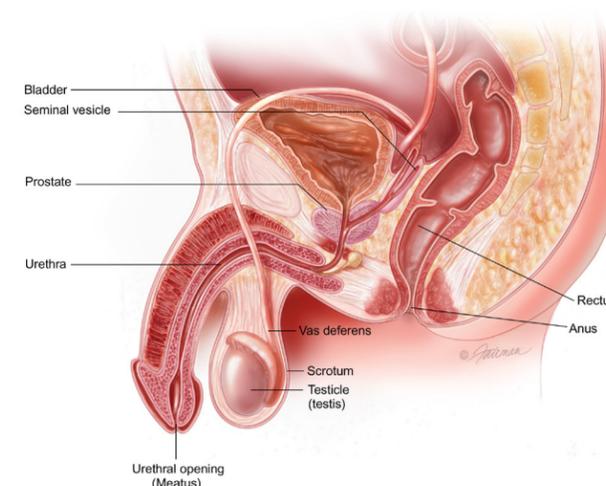
### What is Prostate Cancer?

Prostate cancer is when abnormal cells form and grow in the prostate gland. Not all abnormal growths, also called **tumors**, are cancerous (malignant). Some are not cancerous (benign).

- **Benign growths**, such as benign prostatic hyperplasia (BPH), are rarely a threat to life. They don't spread to nearby tissue or other parts of the body.
- **Cancerous growth**, such as prostate cancer, can spread (metastasize) to nearby organs and tissues such as the bladder or rectum, or to other parts of the body. If the abnormal growth is removed, it can still grow back. Prostate cancer can be life threatening if it spreads far beyond the prostate (is **metastatic**).

### What is Castration-Resistant Prostate Cancer (CRPC)?

Castration-resistant prostate cancer (CRPC) is a form of advanced prostate cancer. CRPC means the prostate cancer is growing or spreading even though testosterone levels are low from **hormone therapy**. Hormone therapy is also called androgen deprivation treatment (ADT) and lowers your natural testosterone level. It is given through medicine or surgery to most men with prostate cancer to stop the testosterone "fuel" that makes this cancer grow. That fuel includes male hormones or androgens (like testosterone). Typically, prostate cancer stops growing with hormone therapy, at least for some time. If the cancer cells begin to "outsmart" hormone treatment, they can grow even without testosterone. If this happens, the prostate cancer is considered CRPC.



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

## What is Non-Metastatic Castration-Resistant Prostate Cancer (nmCRPC)?

CRPC can be broken down into the following categories:

- **Non-Metastatic CRPC (nmCRPC)** is prostate cancer that no longer responds to hormone treatment, but it is only found in the prostate.
- **Metastatic CRPC (mCRPC)** is prostate cancer that no longer responds to treatment that lowers testosterone and has spread to other parts of the body such as **lymph nodes** or bones.

## What are the Symptoms of nmCRPC?

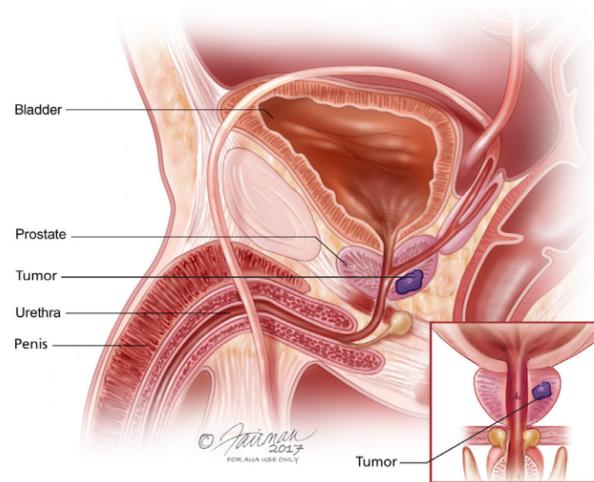
With nmCRPC, the cancer has not spread and there are often no symptoms.

For men with nmCRPC, you can't tell if cancer is growing unless you go to your **urologist** for regular follow-up tests. Blood tests, physical exams and scans are used to track changes. Your health care team will work with you to set the best follow-up schedule.

## What Other Symptoms Should I Consider?

When you have nmCRPC it is worth knowing the symptoms of metastatic CRPC in the event the cancer begins to grow. When men do have symptoms, it may be a sign the cancer has spread beyond the prostate. Symptoms then depend on the size of the tumor(s) and the organs affected. Metastatic CRPC can spread to nearby lymph nodes, then into the bladder, rectum, liver, lungs, and maybe the brain. Signs of mCRPC may begin with trouble urinating, pain or blood in urine. Feeling more tired or weak than normal, weight loss, shortness of breath, or bone pain are also signs.

It's often difficult for men to talk about their symptoms, or tell their doctor. Most men don't know if a certain pain or problem is related to the cancer. Please don't keep symptoms to yourself. It's very important to tell your doctor about anything that doesn't feel normal.



## GET DIAGNOSED

Even if you've already been diagnosed with prostate cancer, your health care provider will want to observe changes over time. This information will help direct your treatment options.

The following tests are used to diagnose and track prostate cancer:

### Blood Tests

The prostate-specific antigen (PSA) blood test measures a protein in your blood called the prostate-specific antigen (PSA). PSA is made only by the prostate and prostate cancers. Results for this test are usually shared as nanograms of PSA per milliliter (ng/mL) of blood.

The PSA test is used to look for changes to the way your prostate produces PSA. It is used to stage cancer, plan treatment, and track how well treatment is going. A rapid rise in PSA may be a sign that something is wrong. When your PSA rises while you are on androgen deprivation treatment (ADT), it may be the first indicator of CRPC. Your doctor may want to repeat the PSA test to confirm the rise.

In addition, your doctor may want to test the level of testosterone in your blood. A rising PSA despite castrate testosterone levels (less than 50 ng/dL) may confirm a diagnosis of CRPC. If your doctor believes that you have CRPC, they may want to conduct imaging tests to make sure it is not metastatic.

## Digital Rectal Exam (DRE)

The **Digital Rectal Exam (DRE)** is a physical exam used to help your doctor feel for changes in your prostate. This test is also used to screen for and stage cancer, or track how well treatment is going. During this test, the doctor feels for an abnormal shape or thickness to the gland. The DRE is often done with the PSA together. For this exam, the health care provider puts a lubricated gloved finger into the rectum.

## Imaging and Scans

Imaging helps doctors learn more about your cancer. Some types are:

- **Magnetic resonance imaging (MRI):** MRI scans can give a very clear picture of the prostate and show if the cancer has spread into the seminal vesicles or nearby tissue. A contrast dye is often injected into a vein before the scan to see details. MRI scans use radio waves and strong magnets instead of x-rays
- **Computed tomography (CT) scan:** The CT scan is used to see cross-sectional slices of tissue and organs. It combines x-rays and computer calculations for detailed images from different angles. It can show solid vs. liquid structures, so it is used to diagnose masses in the urinary tract. CT scans are not as useful as magnetic resonance imaging (MRI) to see the prostate gland itself.
- **Positron emission tomography (PET) scan:** PET scans help your doctor better see where and how much the cancer is growing. A special drug is given through your

## GET TREATED

Prostate cancer can be difficult to treat. The goal of treatment is to help slow the progression of the disease.

It's important to talk with more than just one urologist or **oncologist** with expertise in treating prostate cancer. Getting more than one treatment opinion can help you feel more confident about the treatment path you choose.

There are treatments available for nmCRPC. In this guide, we share information about the treatment choices for men with nmCRPC.

### Hormone Therapy

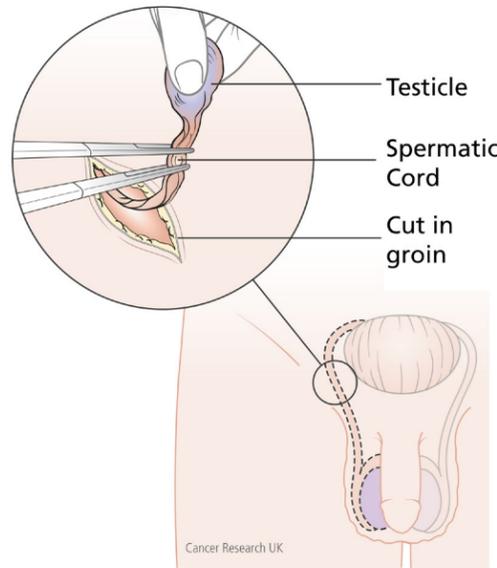
Hormone therapy is any treatment that lowers a man's androgen levels, which are the male sex hormones. It is also called ADT: androgen deprivation therapy. Testosterone is the main fuel for prostate cancer cells, so blocking it can slow the growth of those cells. This process is also called medical castration. Hormone therapy does not cure the cancer. It can slow cancer growth in men whose prostate cancer has metastasized (spread) or returned after other treatments. It may also be used to shrink a local tumor.

There are several types of hormone therapy for prostate cancer treatment. Your doctor may prescribe a variety of

ADT therapies over time to see which works best.

## Surgery for Hormone Therapy

A man's testicles make the hormone testosterone. Surgery to remove the testicles is called **orchietomy** or **castration**. When the testicles are removed, it stops the body from making the hormones that fuel prostate cancer.



Orchietomy is a fairly simple surgery. It is usually done as an outpatient procedure. The surgeon makes a small cut in the scrotum (the sac that holds the testicles). The testicles are then detached from blood vessels and removed. The vas deferens (the tube that carries sperm to the prostate before ejaculation) is removed and the sac is sewn up.

Orchietomy treatment is the surgical form of ADT and does what it aims to do right away – drop testosterone levels. Men who choose this therapy want a one-time surgical treatment. They must be healthy enough to have the surgery, and willing to have their testicles permanently removed.

The main risks from this surgery are infection and bleeding. Many men feel uncomfortable with orchietomy because it is not reversible. The scrotum looks empty. Concerns about body image or self-image may lead men to choose another treatment.

## Other Hormone Therapy

Hormone therapies are available for nmCRPC. Different kinds are available as injections or to be taken by mouth as a pill. Some medications may delay the spread of prostate cancer by blocking receptors in prostate cells that cause them to grow.

Different types of drugs can help in different ways, so it is of great value to talk with your doctor about your choices.

Before starting any type of hormone therapy, ask about side effects. Learn about how your body could respond to the loss of testosterone, and what you can do to feel better. Low dose or intermittent (not constant) hormone therapy may reduce some of the side effects.

Since prostate cancer can “outsmart” this treatment, it tends to work for only a few years. Over time, the cancer can grow in spite of the low hormone levels. Often, other treatments are used along with hormone therapy to manage CRPC.

## Active Surveillance

Some men choose surveillance for nmCRPC. Active surveillance is often used if you have a small, slow growing cancer. It may be good for men who do not have symptoms or want to avoid sexual, urinary or bowel side effects for as long as possible. Others may choose surveillance due to their age or overall health. Active surveillance is mainly used to delay or avoid aggressive therapy. Good candidates for active surveillance are men who have a lower risk of advancing to metastatic cancer.

This method may require you to have many tests over time to track cancer growth. This lets your doctor know how things are going, and prevents treatment-related side effects. This will also help you and your health care team focus on managing cancer-related symptoms. Talk with your care team about whether this is a good choice for you.

## Clinical Trials

Clinical trials are research studies that test new treatments or learn how to use existing treatments better. Clinical studies aim to find the treatment strategies that work best for certain illnesses or groups of people. For some patients, taking part in a clinical trial may be the best treatment.

You may qualify for one, and it may offer you hope. Talk with your doctor about whether you qualify for a clinical trial. Learn about the risks and benefits of the treatment being studied.

Clinical trials follow strict scientific standards. These standards protect patients and help produce reliable study results. You will be given either a standard treatment or the treatment being tested. All of the approved treatments used to treat or cure cancer began in a clinical trial.

To search for information on current or recent clinical trials for the treatment of prostate cancer, visit **UrologyHealth.org/ClinicalTrials**.

## OTHER CONSIDERATIONS

### Follow-Up Care

You and your doctor will set a reasonable schedule of office visits for tests and follow-up over time. There are certain symptoms that your doctor should know about right away, such as blood in your urine or bone pain. You should ask what symptoms to tell your health care team about. You may want to keep a diary of how you're feeling so you can remember.

Look at the sample “Questions to Ask Your Doctor” listed at the end of this section to stay informed about your care.

### Erectile Dysfunction (ED)

Men may have sexual health problems following their cancer diagnosis or treatments. Erectile dysfunction (ED) is when a man finds it hard to get or keep an erection strong enough for sex. ED happens when there is not enough blood flow to the penis, or when nerves to the penis are harmed.

Cancer in the prostate, colon, rectum and bladder are the most common cancers that can affect a man's sexual health. Treatments for cancer, along with emotional stress, can lead to ED.

The chance of ED after prostate cancer treatment depends on many things:

- Age
- Overall health
- Medications you take
- Sexual function before treatment
- Cancer Stage
- Damage to your nerves or blood vessels from surgery or radiation

There are treatments that can help ED. They include pills, vacuum pumps, urethral suppositories, penile injections and implants. Treatment is very individualized. Some treatments may work better for you than others. They have their own set of side effects. A health care provider can talk with you about the pros and cons of each method. They can help you decide which single or combination of treatments is right for you.

### Incontinence

Incontinence can sometimes result from prostate cancer treatment. This is the inability to control the release of urine.

There are different types of incontinence:

- Stress Incontinence (SUI) — Urine leaks when coughing, laughing, sneezing or exercising. This is the most common type.
- Urge Incontinence — The sudden urge or need to go to the bathroom, even when the bladder isn't full because the bladder is overly sensitive. This is also called overactive bladder (OAB).

*“We fear what we don't know. Learn what the side effects can be. Make sure you lay all the cards on the table. Ask any and all questions. It helps.”*

*—Phil, nmCRPC patient*

- Mixed Incontinence — A combination of stress and urge incontinence with symptoms from both types.

Because incontinence may affect your physical and emotional recovery, it is important to understand how to manage this problem.

Treatment for incontinence depends on the type and severity of the problem:

- Kegel Exercises – can strengthen your bladder control muscles.
- Lifestyle Changes – can improve your urinary functions. Try eating healthier foods, limiting smoking, losing weight, making timed visits to the bathroom.
- Medication – can help improve bladder control. They affect the nerves and muscles around the bladder.
- Neuromuscular Electrical Stimulation – strengthens bladder muscles.
- Surgery - to control urination. Could include injecting collagen to tighten the bladder sphincter, implanting a urethral sling to tighten the bladder neck, or an artificial sphincter device.
- Products - There are also many pads and products available that do not treat incontinence but help you stay dry.

## Lifestyle Changes

### Diet

A healthy diet may increase your energy levels and enhance your immune system.

It's important to think about the foods you eat, and try to maintain a healthy weight. Healthy eating habits can improve your health and risks.

Healthy food choices may include:

- o Plenty of fruits and vegetables
- o High fiber foods
- o Low fat foods
- o Limited amounts of simple sugars
- o Limited amounts of processed foods (especially processed meats, like deli foods and bacon)

Because prostate cancer treatment can affect your appetite, eating habits, and weight, it is important to try your best to eat healthy. If you have a hard time eating well, reach out to a registered dietitian/nutritionist (RDN). There are ways to help you get the nutrition you need.

### Exercise

**Exercise** may improve your physical and emotional health. It can also help you manage your weight, maintain muscle and bone strength, and help manage side effects.

If approved by your doctor, men may want to strive to exercise about one to three hours per week. This can include walking or more intense exercise. Physical exercise may help you to:

- o Reduce anxiety
- o Improve energy
- o Improve self-esteem
- o Feel more hopeful
- o Improve heart health
- o Reach a healthy weight
- o Boost muscle strength

**Pelvic floor exercise** may help men being treated for prostate cancer. The pelvic floor is a group of muscles and structures in your pelvis between your legs. The pelvic floor supports the bowel, bladder, and sexual organs. They help with urinary and fecal functions as well as sexual performance. The muscles contract and relax, just like any other muscle in your body. Pelvic floor exercises can help with side effects like **erectile dysfunction** and urinary incontinence. More information about this is in the "After Treatment" section.

## Emotional Support

Start with a team of doctors that you feel good about, that you understand, and that spend time listening to you. You can interview several doctors until you find a team you like. It's important to be open with your doctors and get answers to your questions. You should try your best to talk about your concerns.

Another great resource is a prostate cancer support group. Men in a support group know what you're going through better than anyone else. It helps to talk with other men who've been there, managing similar concerns. These men can offer information, hope and even laughter in the face of pain.

You can also feel emotionally stronger with spirituality. Spirituality can include meditation, connecting with nature, prayer or other religious practices. Establishing a connection between yourself and a greater power helps add perspective to our lives. It enhances the appreciation for life during the battle with prostate cancer.

In addition, some find it helpful to be in control of your legal paperwork. The most important items to consider are: durable power of attorney, a living will and a conventional will. If you haven't already, aim to get these things in order for you and for the people you love.

Maintaining hope in the face of cancer is not always easy or possible. Hope is a way of thinking, feeling and acting. It is an essential tool for managing and adjusting to an illness as serious as cancer. Consider hope in different ways, every day. If you feel hopeless, consider talking to a licensed therapist who knows about working with patients who have cancer.

## QUESTIONS TO ASK YOUR DOCTOR

### Questions to Ask your Doctor about Prostate Cancer

- What kind of prostate cancer do I have – and how fast is it growing?
- What do the changes in my PSA level mean over time?
- Do I need any other tests to decide what care is best for me?
- Are you sure my cancer hasn't spread outside of my prostate?
- What tests should we do to make sure my cancer hasn't spread?
- What other physical issues should I tell you about?
- What are "skeletal related events"?
- How often should I come to you for follow-ups?

### Questions to Ask About Care

- What are my next steps?
- Should I keep taking the same hormone treatment?
- Would active surveillance be good for me?
- Are there clinical trials I should know about?
- What are the pros and cons of each treatment option?
- What can I do to protect my bones?
- Will vitamin D help me, or should I make other dietary changes?
- Can you refer me to a dietician?
- What else can I do to slow down cancer growth?
- Can you give me the name of another doctor for a second opinion?
- Can you put me in touch with a support group?

## GLOSSARY

### BENIGN GROWTHS

A tissue growth that is not cancerous.

### BIOPSY

Samples of prostate tissue are removed and observed under a microscope. The cells are carefully looked at to see if they contain cancer or other abnormal cells.

### BLADDER

A hollow, balloon – shaped organ which urine is stored before it moves through the urethra.

### CASTRATION

The removal of testicles or the male hormones created by the testicles.

### CT SCAN

Also called computerized axial tomography (CAT) scan. This procedure uses both x-rays and computer technology to produce detailed images of the body.

### EJACULATION

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

### ERECTILE DYSFUNCTION (ED)

Problems getting or keeping an erection.

### GLEASON SCORE

The most common grading system for prostate cancer. Cells are given a score from two (least aggressive) to ten (most aggressive).

### HORMONE THERAPY

Uses medications to decrease or block testosterone and other male hormones. The purpose of hormone therapy is to stop or slow the growth of prostate cancer.

### LYMPH NODES

Rounded masses of tissue that produce cells to fight invading germs or cancer.

### MAGNETIC RESONANCE IMAGING (MRI)

A procedure that uses a magnetic field and radio waves to create detailed images of the organs and tissues in the body.

### METASTATIC

Cancer that spreads beyond its point of origin. For example, spreads from the prostate to the bladder.

### ONCOLOGIST

A doctor specializing in the treatment of cancer.

### ORCHIECTOMY

Surgery to remove the testicles.

## **PATHOLOGIST**

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

## **PENIS**

The male organ used for sex and going to the bathroom.

## **PET SCAN**

A special drug (a tracer) given through your vein, or you may inhale or swallow the drug. Your cells will pick up the tracer as it passes through your body. When the scanner passes, the tracer allows your doctor to better see where and how much the cancer is growing.

## **PROSTATE**

In men it is a walnut-shaped gland below the bladder that surrounds the urethra. The prostate makes fluid that goes into semen.

## **PSA (PROSTATE-SPECIFIC ANTIGEN)**

A protein made only by the prostate. High levels of PSA in the blood may be a sign of cancer or other prostate health issues.

## **RECTUM**

The lower part of the bowel ending in the anal opening.

## **SEMEN**

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

## **SEMINAL VESICLES**

A gland that helps produce semen.

## **TESTICLES**

Glands that are inside the scrotum, the pouch below the penis. They produce sperm and the male hormone testosterone.

## **TISSUE**

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

## **TUMOR**

An abnormal mass of tissue or growth of cells.

## **URETHRA**

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

## **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. Urologists also specialize in male and female sexual dysfunction and issues.

## **Notes**

## 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.

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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