

Advanced Prostate Cancer Patient Guide



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This patient guide is also available in Spanish. • Esta guía para el paciente también está disponible en español.

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Patient Story

When I was 55 years old, I had a slightly elevated prostate-specific antigen (PSA) of a little over 5. I went ahead and had a biopsy. The biopsy came back negative. I assumed I was fine; I felt fine. I stayed fit and ran 15-20 miles a week. After a few years, my wife, a nurse, would say, “You have to go and get yourself tested.” Finally at 60, she said “Phil, get a physical!” I did. The PSA level was up to 30. The most recent biopsy said I had advanced stage prostate cancer with a Gleason score of 10. I was still running daily and had no sense that I had cancer.

It was really tough to figure out what to do. I felt my choices were limited because the cancer was so advanced. When I look back now, I wish I did not wait so long to be tested again. We have to be our own advocates. We have to be reminded that bad stuff can happen if we do not keep tabs on our health.

When diagnosed with advanced cancer, I was fearful of the unknown. What helped me most was to learn everything I could about my options. I began to learn what I could do and what to expect, and it helped. By learning everything I could, it helped me make treatment decisions along with my doctor. I asked a lot of questions.

Whether we are talking with a surgeon or radiation oncologist, people should not be afraid to ask questions and get second opinions. We must learn everything we can about treating prostate cancer and about the side effects of treatment.



It was tough when I had to deal with the side effects, like impotence and incontinence. Fortunately, I had surgeries to correct these problems. I am not the same as I was before, but I am alive and well. I have learned to accept, appreciate and deal with my own situation.

Find someone to talk with. I work as a prostate cancer recovery coach. I help the newly diagnosed talk through what to expect. I like to help others because, for me, it helped to be able to talk to someone else who had been there. I also recommend going to support groups. You have to be open to talking about what you are going through. People can feel better after talking to someone else who has been there. **Photo is not of actual patient.*

Introduction

This patient guide is meant for all people with a **prostate*** gland. It is of great value to know that all people who are born genetically male have a prostate. Any gender can have a prostate and everyone with a prostate should know about prostate cancer. Prostate cancer is the second most common cancer in men in the United States. About one in eight people with prostates will be diagnosed with prostate cancer during their lifetime. Prostate cancer is more likely to develop in older people and in African Americans. Learning you have advanced prostate cancer may be unsettling. You may have a lot to think about, including treatment choices and your future.

You are not alone during your advanced prostate cancer journey. Your journey may include a team with a primary care physician, **genetic counselor, oncologist, urologist**, pharmacist, social worker, **palliative care** team and other health care providers, as well as your family and friends. With advanced prostate cancer, this type of team care may

be called **precision (personalized) medicine**. Many patients may also work with nurse navigators, also known as patient navigators. These health care professionals help a person with cancer “navigate” the hospital and human services that come along with a cancer diagnosis. This may include helping with decision-making, coordinating services and advocating for the patient with the other members of the health care team. Navigators strive to identify the barriers and eliminate them to help the patient avoid delays in care.

Learning about your prostate, prostate cancer, tests, treatments and side effects may help you during this journey. Your treatment choices should be based on your personal preferences, health and age and should be fully discussed with your health care team. In this patient guide, we provide you with information about advanced prostate cancer to help you during your prostate cancer journey.

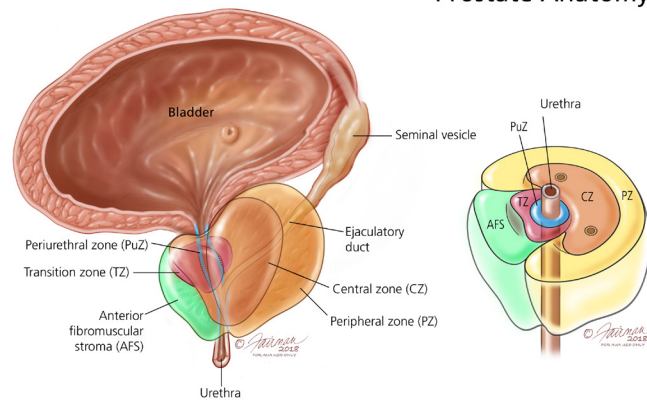
GET THE FACTS

What is the Prostate?

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 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** mixes with the sperm. This mixture—semen—goes through the urethra and out of the penis.

Prostate Anatomy



What is Prostate Cancer?

Cancer is the result of abnormal cell growth that takes over the body's normal cell function, making it harder for the body to work the way it should. Prostate cancer develops when abnormal cells form and grow in the prostate gland. Not all abnormal growths, also called **tumors**, are cancerous (malignant). Some tumors are not cancerous (benign).

- **Benign growth**, such as **benign prostatic hyperplasia (BPH)**, is not life-threatening and does not 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 well beyond the prostate (**metastatic** disease).

Prostate cancer cells spread when they break away from a prostate tumor. They can travel through blood or **lymph nodes** to reach other parts of the body. After spreading, cancer cells may attach to other tissues. They can form new tumors that may damage those tissues.

When prostate cancer spreads to another part of the body, the new growth has the same type of cells. For example, if prostate cancer spreads to the bones, the cancer cells found there are still prostate cancer cells. For this reason, the disease is called “metastatic prostate cancer” and not bone cancer. It is treated as prostate cancer, no matter where it is found.

What is Advanced Prostate Cancer?

When prostate cancer spreads beyond the prostate or returns after treatment, it is often called advanced prostate cancer. Prostate cancer is often grouped into four stages, with stage IV being more advanced prostate cancer.

Stages of Prostate Cancer

- **Early-Stage | Stages I & II:** The tumor has not spread beyond the prostate.
- **Locally Advanced | Stage III:** Cancer has spread outside the prostate but only to nearby tissues.
- **Advanced | Stage IV:** Cancer has spread outside the prostate to other parts such as the lymph nodes, bones, liver or lungs.

When an early-stage prostate cancer is found, it may be treated or placed on **active surveillance** (watching closely). Advanced prostate cancer is not “curable,” but there are many ways to treat it. Treatment can help slow advanced prostate cancer progression and may help manage symptoms.

There are many types of advanced prostate cancer:

Biochemical Recurrence

With **biochemical recurrence**, the **prostate-specific antigen (PSA)** level has risen after therapy using surgery and/or **radiation**, with no other sign of cancer.

Metastatic Prostate Cancer

Cancer cells have spread beyond the prostate. Cancer spread may be seen in imaging studies and may show the cancer has spread. Prostate cancer is metastatic if it has spread to these areas:

- Lymph nodes outside the **pelvis**
- Bones
- Other organs, such as the liver or lungs

You may be diagnosed with metastatic prostate cancer when you are first diagnosed, after having completed your first treatment or even many years later. It is not common to be diagnosed with metastatic prostate cancer on first diagnosis, but it does happen.

Metastatic Hormone-Sensitive Prostate Cancer (mHSPC)

Metastatic hormone-sensitive prostate cancer (mHSPC), also known as metastatic castration-sensitive prostate cancer (mCSPC), is when cancer has spread past the prostate into the body and is responsive to **hormone therapy** or the patient has not yet had hormone therapy.

This means that levels of male sex hormones, including androgens like testosterone, can be reduced to slow cancer growth. Unchecked, these male sex hormones “feed” the prostate cancer cells to let them grow. Hormone therapy, like **androgen deprivation therapy (ADT)**, may be used to reduce the levels of these hormones.

Castration-Resistant Prostate Cancer (CRPC)

Castration-resistant prostate cancer (CRPC) is a form of advanced prostate cancer. CRPC means prostate cancer is growing or spreading even though testosterone levels are low from hormone therapy. Hormone therapy is also called testosterone depleting therapy or androgen deprivation therapy (ADT) and can help lower your natural testosterone level. It is given through medicine or surgery to most people with advanced prostate cancer to reduce the testosterone “fuel” that makes this cancer grow. That fuel includes male hormones or androgens (like testosterone). Typically, prostate cancer growth slows down 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, prostate cancer is considered CRPC.

Non-Metastatic Castration-Resistant Prostate Cancer (nmCRPC)

Prostate cancer that no longer responds to hormone treatment and is only found in the prostate. This is found by a rise in the PSA level, while the testosterone level stays low. Imaging tests do not show signs the cancer has spread.

Metastatic Castration-Resistant Prostate Cancer (mCRPC)

Metastatic castration-resistant prostate cancer is when cancer has spread past the prostate into the body and it is able to grow and spread even after treatments were used to lower testosterone levels. The PSA levels keep rising and metastatic spots are present/growing. This is disease progression despite medical or surgical castration.

Signs and Risk Factors of Advanced Prostate Cancer

Signs

People with advanced prostate cancer may or may not have any signs of sickness. Symptoms depend on the size of the new growth and where the cancer has spread in the body. With advanced disease, mainly if you have not had treatment to the prostate itself, you may have problems passing urine or see blood in your urine. Some may feel tired, weak or lose weight. When prostate cancer spreads to bones, you may have bone pain. Tell your health care team about any pain or other symptoms you feel. There are treatments that may help.

Risks

Your risk for prostate cancer rises as you get older, have a family history of prostate cancer, are African American or have inherited mutations such as the BRCA1 or BRCA2 genes.

- **Age:** Prostate cancer risk increases with age. About 6 in 10 cases of prostate cancer are found in those older than 65. Prostate cancer is rare in those under the age of 40.
- **Race/ethnicity:** People who are African American and those who are Caribbean of African ancestry face a higher risk for being diagnosed with prostate cancer. They are also more likely to be diagnosed with prostate cancer at younger ages. It is not clear why prostate cancer affects African Americans more than other racial/ethnic groups.
- **Genetic Factors:** The risk of prostate cancer more than doubles in those with a family history of prostate cancer in their grandfathers, fathers or brothers. Having family members with breast and ovarian cancer also raises the risk for prostate cancer. That is because some genes, including BRCA1 and BRCA2, increase the risk of multiple cancers such as breast, ovarian and prostate cancers. If a person has a mutation in any of these genes, they should be screened earlier and/or more often for prostate cancer.

As a health care tool, gene testing results can help determine whether a certain treatment may be helpful. Your health care team may suggest gene testing because of family history or because you have aggressive prostate cancer.

To learn more, talk to your health care team about inherited (**genetic / germline**) and acquired (**biomarker / genomic / somatic**) tests as these may reveal other ways to treat prostate cancer.

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

DIAGNOSIS

Advanced cancer may be found before, at the same time or later than the main tumor. Most diagnosed with advanced prostate cancer have had **biopsy** and treatment in the past. When a new tumor is found in someone who has been treated for cancer in the past, usually cancer has spread. Even if you have already been diagnosed with prostate cancer, your health care provider may want to observe changes over time. The following tests are used to diagnose and track prostate cancer.

Blood Tests

The PSA blood test measures a protein in your blood called the prostate-specific antigen (PSA). Only the prostate and prostate cancers make PSA. 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 something is wrong. In addition, your health care team may want to test the level of testosterone in your blood.

When a PSA level doubles within a number of months, this is also known as **PSA doubling time (PSADT)**. If your PSA increases after surgery, your health care team may want to measure how fast it is rising as this may be a sign of cancer.

Digital Rectal Exam

The **digital rectal exam (DRE)** is a physical exam to feel for changes in your prostate. This test may also be used to screen for and stage cancer or track how well treatment is going. During this test, a health care team member feels for an abnormal shape, consistency, nodularity or thickness to the prostate gland. For this exam, the health care provider puts a lubricated gloved finger into the rectum.

Imaging and Scans

Imaging helps your health care team learn more about your cancer. Some types are:

- **Magnetic resonance imaging (MRI):** An **MRI scan** 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 views of tissue and organs. It combines x-rays and computer calculations for detailed images from different angles. It can show solid versus liquid structures, so it is used to diagnose masses in the **urinary tract**. CT scans are not always as useful as MRI to see the prostate gland itself but are very good at evaluating surrounding tissues and structures.
- **Positron emission tomography (PET) scan:** The **PET scan** may help your health care team better see where and how much the cancer is growing. A special drug (called a tracer) is 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. The scanner helps to better see where and how much the cancer is growing.
- **Bone scan:** A **bone scan** can help show if cancer has reached the bones. If prostate cancer spreads to distant sites, it often goes to the bones first. In these studies, a radionuclide dye is injected into the body. Over a few hours, images are taken of the bones. The dye helps to make images of cancer show up more clearly.

Biopsy

People diagnosed with advanced prostate cancer from the beginning may start with a prostate biopsy. It is also used to grade and stage cancer. Most diagnosed with advanced prostate cancer have had a prostate biopsy in the past. When a new tumor is found in someone who has been treated before, it is usually cancer that has spread.

A biopsy is a tissue sample taken from your prostate or other organs to look for cancer cells. There are many approaches to prostate biopsies. These can be done through a probe placed in the rectum, through the skin of the perineum (between the scrotum and rectum), and may use a specialized imaging device, such as MRI. The biopsy removes small pieces of tissue for review under a microscope. The biopsy takes 10 to 20 minutes. A **pathologist** (an expert who classifies disease) looks for cancer cells within the samples. If cancer is seen, the pathologist will "grade" the tumor.

Staging and Grading

Prostate cancer is grouped into four stages. The stages are defined by how much and how quickly the cancer cells grow. The stages are defined by the **Gleason Score** and the T (tumor), N (node), M (metastasis) Score.

Gleason Score

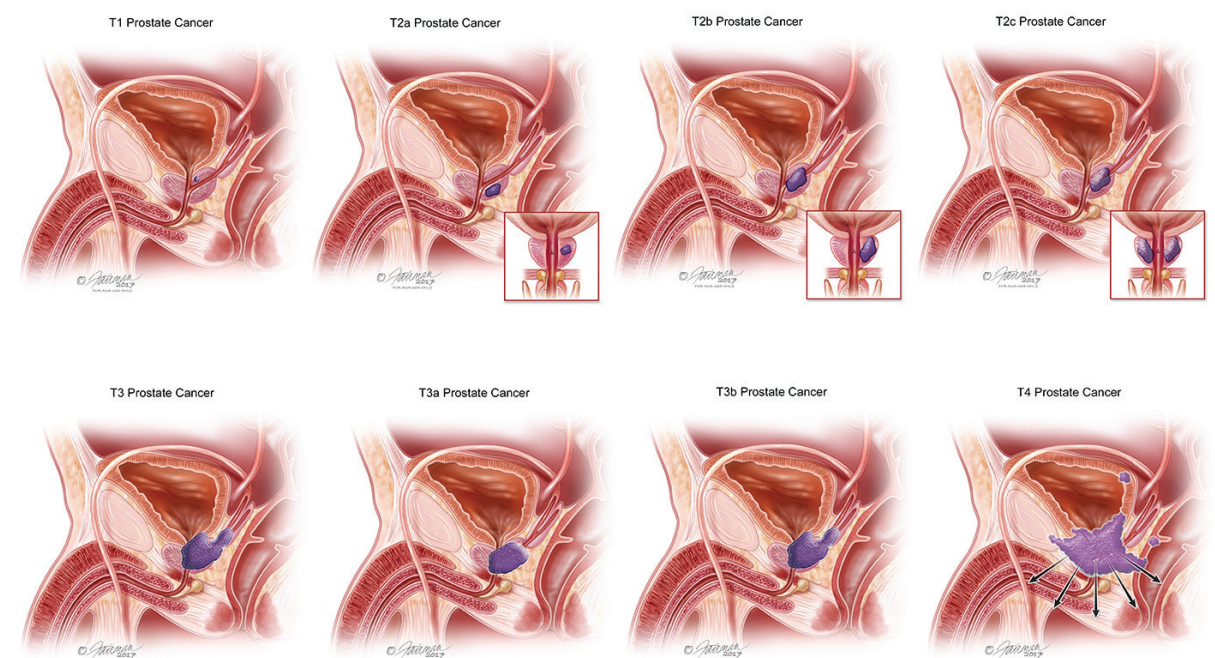
If a biopsy results in cancer, the pathologist gives it a grade. The most common grading system is called the Gleason grading system. The Gleason score is a measure of how quickly cancer cells can grow and affect other tissue. Biopsy samples are taken from the prostate and given a Gleason grade by a pathologist. Lower grades are given to samples with small, closely packed cells. Higher grades are given to samples with more spread-out cells. The Gleason score is set by adding together the two most common grades found in a biopsy sample.

The Gleason score will help your health care team understand if the cancer is a low-, intermediate- or high-risk disease. The risk assessment is the risk of **recurrence** after treatment. Generally, Gleason scores of 6 are treated as low-risk cancers. Gleason scores of around 7 are treated as intermediate/mid-level cancers. Gleason scores of 8 and above are treated as high-risk cancers. Some of these high-risk tumors may have already spread by the time they are found.

Staging

Tumor, Nodes and Metastasis (TNM) staging system is the system used for tumor staging. The T, N, M Score is a measure of how far prostate cancer has spread in the body. The T (tumor) score rates the size and extent of the original tumor. The N (nodes) score rates whether the cancer has spread into nearby lymph nodes. The M (metastasis) score rates whether the cancer has spread to distant sites.

Tumors found only in the prostate are more successfully treated than those that have metastasized (spread) outside the prostate. Tumors that have metastasized are incurable and require drug-based therapies to treat the whole body.



Prostate Cancer Stage Groupings

Prostate cancer is staged as:

- T1: Health care provider cannot feel the tumor
- T1a: Cancer present in less than 5% of the tissue removed and low grade (Gleason less than 6)
- T1b: Cancer present in more than 5% of the tissue removed or is of a higher grade (Gleason greater than 6)
- T1c: Cancer found by needle biopsy done because of a high PSA
- T2: Health care provider can feel the tumor with a DRE, but the tumor is confined to the prostate
- T2a: Cancer found in one half or less of one side (left or right) of the prostate
- T2b: Cancer found in more than half of one side (left or right) of the prostate
- T2c: Cancer found in both sides of the prostate
- T3: Cancer has begun to spread outside the prostate and may involve the seminal vesicles
- T3a: Cancer extends outside the prostate but not to the seminal vesicles
- T3b: Cancer has spread to the seminal vesicles
- T4: Cancer has spread to nearby organs
- N0: There is no sign of the cancer moving to the lymph nodes in the area of the prostate (becomes N1 if cancer has spread to lymph nodes)
- M0: There is no sign of tumor metastasis (becomes M1 if cancer has spread to other parts of the body)

TREATMENT OPTIONS

The goal of advanced prostate cancer treatment is to shrink or control tumor growth and control symptoms. There are many treatment choices for advanced prostate cancer. Which treatment to use, and when, will depend on discussions with your health care team. It is important to talk to your health care team about your treatment options, including potential side effects before you choose a plan.

Hormone Therapy

Hormone therapy is a treatment that can help lower testosterone, or hormone, levels. This therapy is also called androgen deprivation therapy (ADT). Testosterone, an important male sex hormone, is the main fuel for prostate cancer cells, so reducing its levels may slow the growth of those cells. Hormone therapy may help slow prostate cancer growth when prostate cancer has metastasized (spread) away from the prostate or returned after other treatments. Some treatments may be used to shrink or control a local tumor that has not spread.

There are several types of hormone therapy for prostate cancer treatment, including medications and surgery. You may be prescribed a variety of therapies over time.

Hormone Therapy with Medications

There are different types of hormone therapies available as injections or as pills. Some of these therapies help limit the body from producing luteinizing hormone-releasing hormone (LHRH, also called gonadotrophin releasing hormone, or GnRH). LHRH triggers the body to make testosterone. Other therapies help limit prostate cells from being affected by testosterone by inhibiting hormone receptors. A blood test is sometimes done to check testosterone levels after treatment is started. You may also have tests to monitor your bone density during treatment.

With LHRH treatment there is no need for surgery to remove the testicles. Candidates for this treatment include those who cannot or do not wish to have surgery to remove their testicles.

There are different types of medical hormone therapy you may be prescribed to lower your body's production of testosterone or inhibit testosterone. After your testosterone levels drop to a very low level, you are at "castration level." Once testosterone levels drop, prostate cancer cells may decrease in growth and/or proliferation.

Types of Medications

- **LHRH/GnRH drugs (androgen deprivation therapy - ADT):** LHRH/GnRH are drugs that lower testosterone

levels. They may be used whether or not the cancer has spread. There are two types, agonists and antagonists.

Agonists (analogues) cause the body to produce a burst of testosterone (called a "flare"). Agonists are longer acting than natural LHRH. After the initial flare, the drug tricks your brain into thinking it does not need to produce LHRH/GnRH because it has enough. As a result, the testicles are not stimulated to produce testosterone. LHRH or GnRH agonists are given as shots or as small pellets placed under the skin. Based on the drug used, they could be given once every one, three or six months.

Antagonists also lower testosterone. Instead of flooding the pituitary gland with LHRH, they help limit LHRH from binding to receptors. There is no testosterone flare with an LHRH/GnRH antagonist because the body does not get the signal to produce testosterone. Antagonists may be taken by mouth or injected (shot) under the skin, in the buttocks or **abdomen**. The shot is given in the health care provider's office. You will likely stay in the office for a short period of time after the shot to ensure you do not have an allergic reaction.

After treatment has started, a blood test makes sure testosterone levels have dropped. You may also have tests to monitor bone density.

- **Antiandrogen drugs:** Antiandrogen drugs are taken as pills by mouth. These treatments work by inhibiting the androgen receptors in the prostate cancer cells. Normally, testosterone would bind with these receptors to fuel growth of prostate cancer cells. With the receptors inhibited, there is less testosterone to "feed" the prostate. Using certain antiandrogens a few weeks before, or during, LHRH therapy may reduce flare-ups. Antiandrogens may also be used after surgery or castration when hormone therapy stops working.
- **CAB (combined androgen reducing treatment, with antiandrogens):** This method blends castration (by surgery or with the drugs described above) and antiandrogen drugs. The treatment reduces production of testosterone and can help limit it from binding to cancer cells.
- **Androgen synthesis inhibitors:** These drugs help limit other parts of your body (and the cancer itself) from making more testosterone and its metabolites. Those newly diagnosed with metastatic hormone sensitive prostate cancer (mHSPC) or people with metastatic

Surgery or taking oral drugs may be ways to lower the testosterone made by your testicles. The rest of the testosterone is made by the adrenal glands. Antiandrogen therapy limits testosterone made by the adrenal glands.

castration-resistant prostate cancer (mCRPC) may be candidates for this therapy.

Androgen synthesis inhibitors may be taken by mouth as a pill. This drug helps limit your body from releasing the enzyme needed to make androgens in the adrenal glands, testicles and prostate tissue, resulting in reduced levels of testosterone and other androgens. Because of the way it works, this drug must be taken with an oral steroid.

- **Androgen receptor binding inhibitors:** These drugs limit testosterone from linking to prostate cancer cells (like antiandrogens). These drugs may be used in certain types of advanced prostate cancer.

Androgen receptor binding inhibitors are taken as pills. You do not need to take steroids with this type of drug. This type of drug inhibits the androgen receptor at multiple sites to slow down the growth of cancer cells. These drugs may slow down the spread of cancer.

Hormone Therapy with Surgery

Surgery to remove the testicles for hormone therapy is called **orchiectomy** or castration. When the testicles are removed, it limits the body from making the hormones that fuel prostate cancer. It is rarely used as a treatment choice in the United States. People who choose this therapy want a one-time surgical treatment. They must be willing to have their testicles permanently removed and must be healthy enough to have surgery.

This surgery allows the patient to go home the same day. The surgeon makes a small cut in the scrotum (sac that holds the testicles). The testicles are detached from blood vessels and removed. The vas deferens (tube that carries sperm to the prostate before ejaculation) is detached. Then the sac is sewn up.

There are potential benefits to undergoing orchiectomy to treat advanced prostate cancer. It is simple and has few risks. It only needs to be performed once. It is effective right away. Testosterone levels drop dramatically.

Removing the testicles limits the body from making testosterone. Some choose to have artificial testicles or saline implants placed in the scrotum to help the scrotum look the same as before surgery. Some people choose another surgery called subcapsular orchiectomy. This removes the glands inside the testicles, but it leaves the testicles themselves, so the scrotum looks normal.

Hormone Therapy Side Effects

Unfortunately, hormone therapy may not work forever, and it does not cure cancer. Over time, the cancer may grow despite the low hormone level (castration-resistant). Other treatments may also be needed to manage the cancer.

Hormone therapies have many possible side effects and it

is important that you learn about these. Intermittent (not constant) hormone therapy may also be a treatment option. Before starting any type of hormone therapy, talk with your health care provider.

Possible hormone therapy side effects may include sexual changes, such as lower sexual desire and/or erectile dysfunction; changes in the way one feels to include mood swings, depression, memory loss, hot flashes and/or fatigue; physical changes in weight, muscle mass, bone strength and/or breast nipple tenderness; other impacts, such as **anemia**, high cholesterol, diabetes or cardiovascular risks.

There are benefits and risks to each type of hormone therapy, so ask questions so you understand what is best for you and how your health care team can help you manage these side effects.

Chemotherapy

Chemotherapy drugs can slow the growth of cancer. These drugs may reduce symptoms and extend life. They may also ease pain and symptoms by shrinking tumors. Chemotherapy is a treatment option for those whose cancer has spread to other parts of the body.

Most chemotherapy drugs are given through a vein (intravenous, IV). During chemotherapy, the drugs move throughout the body. They kill quickly growing cancer cells and non-cancer cells. Chemotherapy may be given before pain starts to prevent pain as cancer spreads to bones and other sites.

Side effects may include hair loss, fatigue, nausea and vomiting. There may be changes in your sense of taste and touch. You may be more prone to infections. You may experience neuropathy (tingling or numbness in the hands and feet). Due to the side effects from chemotherapy, the decision to use these drugs may be based on:

- Your health and how well you can tolerate the drug
- What other treatments you have tried
- If radiation is needed to relieve pain quickly
- What other treatments or clinical trials are available
- Your treatment goals

If you use chemotherapy, your health care team may watch you closely to manage side effects. Talk to your care team to find out how to help manage side effects.

Immunotherapy

Immunotherapy uses the body's immune system to fight cancer. It may be a choice for those with mCRPC who have

no symptoms or only mild symptoms.

If the cancer returns and spreads, your health care team may offer a cancer vaccine to boost your immune system so it can attack the cancer cells. Immunotherapy may be given to mCRPC patients before chemotherapy, or it may be used along with chemotherapy.

Side effects are often experienced in the first 24 hours after treatment and may include fever, chills, weakness, headache, nausea, vomiting and diarrhea. Patients may also have low blood pressure and rashes.

Bone-Targeted Therapy

Bone-targeted therapy may help with prostate cancer that has spread to the bones as they may get “skeletal-related events” (SREs). SREs include fractures, pain and other problems. These drugs may slow the cancer, reduce SREs and help prevent pain and weakness from cancer growing in your bones. Side effects may include flu-like symptoms, bone or joint pain, nausea, diarrhea, and /or feeling weak or tired.

Radiopharmaceuticals are drugs with radioactivity. They can be used to help with bone pain from metastatic cancer. Some may also be used when mCRPC has spread to the bones. They may be offered when ADT is not working. Radiopharmaceuticals give off small amounts of radiation that go to the exact parts where cancer cells are growing.

Drugs used to reduce SREs may help reduce bone turnover. Side effects include low calcium, worsening kidney function and, rarely, destruction of the jawbone.

Calcium and vitamin D are also used to help protect your bones. They are often recommended for people on hormone therapy to treat prostate cancer.

Precision Medicine

Precision (personalized) medicine is a tailored approach to care based on the genes, proteins and other substances in a person’s body. Tailored (targeted) therapies, such as **PARP inhibitors**, may be an option for patients with advanced prostate cancer who have certain germline or somatic mutations. For example, potential treatment options for patients with DNA mutations could include treatment with a PARP inhibitor. Talk with your health care team about the tests and treatment choices that may be right for you with precision medicine.

Your health care team may suggest some combination of treatment options based on the stage of your disease.

Radiation

Radiation uses high-energy beams to kill tumors. Prostate cancer often spreads to the bones. Radiation can help ease pain or prevent fractures caused by cancer spreading to the bone.

There are many types of radiation treatments. Radiation may be given once or over several visits. The treatment is like having an x-ray. It uses high-energy beams to kill tumors. Some radiation techniques focus on saving healthy tissue nearby. Computers and software allow better planning and targeting of radiation doses. Side effects of radiation may include bowel and urinary incontinence, erectile dysfunction, and feeling tired.

Active Surveillance

Active surveillance is mainly used to delay or avoid treatment. It is often used if you have a small, slow-growing cancer. It may be a choice for those 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.

This method may require you to have tests and follow-up visits over time to track cancer growth. This lets your health care team 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 an option.

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

It is of great value to learn about the risks and benefits of the treatment being studied. To search for information on current or recent clinical trials for the treatment of prostate cancer, talk to your health care team or visit UrologyHealth.org/ClinicalTrials.

OTHER CONSIDERATIONS

Follow-up Care

You may schedule office visits for tests and follow-up over time. There are certain symptoms your health care team should know about right away, such as blood in your urine or bone pain, but it is best to ask your health care team about the symptoms you should report. Some people find it helpful to keep a diary to help remember things to talk about during follow-up visits.

Incontinence

Incontinence is the inability to control the release of urine and can sometimes happen with prostate cancer treatment. There are different types of incontinence:

- **Stress Urinary Incontinence (SUI)**, when urine leaks with coughing, laughing, sneezing or exercising or with any additional pressure on the pelvic floor muscles. This is the most common type.
- **Urge Incontinence**, or the sudden urge to pass urine, even when the bladder is not full, because the bladder is overly sensitive. This might be called overactive bladder (OAB).
- **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. There are treatment choices that may help incontinence. Talk with your health care team before trying any of these options.

- **Kegel exercises** may strengthen your bladder control muscles.
- **Lifestyle changes** may improve your urinary functions. Try eating healthier foods, limiting smoking, losing weight and making timed visits to the bathroom.
- **Medication** may help improve bladder control by affecting the nerves and muscles around the bladder.
- **Neuromuscular electrical stimulation** uses a device to help strengthen bladder muscles.
- **Surgery** to control urination may include injecting collagen to tighten the bladder sphincter, implanting a urethral sling to tighten the bladder neck or an artificial sphincter device.
- **Products**, such as pads, may help you stay dry but do not treat incontinence.

- **Avoiding bladder irritants** that include caffeine, alcohol and artificial sweeteners.

Erectile Dysfunction

Patients 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, such as:

- 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 may help ED. They include pills, vacuum pumps, urethral suppositories, penile injections and implants. Treatment should be 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 and help you decide which single treatment or combination of treatments is right for you.

Lifestyle Changes

Nutrition

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

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

Healthy food choices may include:

- Plenty of fruits and vegetables
- High fiber foods

- Low-fat foods
- Limited amounts of simple sugars
- 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. Always talk with your health care team before making changes to your diet.



Expand Your Journey... through Food!
Scan this QR code with your phone camera to get healthy recipes.



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.

Always talk with your health care team before starting or changing your exercise routine. If approved by your health care team, patients may want to strive to exercise about one to three hours per week. Cardiovascular exercise and strength/resistance training may be good choices. This can include walking or more intense exercise. Physical exercise may help you to:

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

Pelvic floor exercise may help people 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.

Emotional Support

Support groups may help the emotional well-being of people who have prostate cancer. This can be done in person, through social media or through online cancer organizations. People in prostate cancer support groups may be of help because they have prostate cancer too. It may help you to talk with other patients who have managed similar concerns. These groups may offer information, hope and even laughter during your prostate cancer journey.

Hope is important during advanced prostate cancer. Hope is a way of thinking, feeling and acting. It is a tool for managing and adjusting to an illness as serious as cancer. People with advanced prostate cancer can still have hopes and dreams, even if these might have changed since diagnosis. If you feel hopeless, consider talking to a licensed therapist who knows about working with patients who have cancer. You may choose to ask your health care team about seeking the help of a therapist.

Questions to Ask Your Health Care Team

- What does “advanced cancer” mean for me?
- Are there other tests I should have to understand how advanced my cancer is?
- What are the treatment options for this grade/stage of cancer?
- Which treatment do you recommend for me and why?
- How long should I try a treatment type before we know whether it works?
- Would a clinical trial be an option for me?
- What can I do to manage my symptoms?
- What are the side effects to my treatment options and are there ways that might help manage them?
- What can I do to protect my bones?
- What is the average lifespan for people managing my grade/stage of cancer?
- What kind of care will I receive to keep me comfortable if I decide not to have active treatment?
- Can you refer me to another expert for a second (or third) opinion?
- Can you refer me to a dietitian?
- Can you put me in touch with a support group?
- How can I help my overall health?

GLOSSARY

Abdomen

Also known as the belly. The part of the body that holds all internal structures between the chest and the pelvis.

Active Surveillance

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

Androgen Deprivation Therapy (ADT)

A type of hormone therapy used to help lower testosterone and other male hormone levels. The purpose of hormone therapy is to limit or slow the growth of prostate cancer.

Anemia

This is a low red blood cell count that may cause tiredness or weakness as less oxygen is getting to tissues and organs.

Benign Prostatic Hyperplasia (BPH)

Enlarged prostate not caused by cancer; symptoms include problems passing urine because as the prostate grows, it places pressure on the urethra.

Biochemical Recurrence

The prostate-specific antigen (PSA) level has risen after treatment(s) using surgery or radiation. This may occur in patients who do not have symptoms or have any other sign of cancer.

Biomarker Tests

Tests to look for acquired mutations that occur randomly to measure what is happening in a cell or organism. The results may help experts diagnose, watch and treat your cancer.

Biopsy

Samples of tissue are removed for review under a microscope to see if they contain cancer or other abnormal cells.

Bladder

The balloon-shaped pouch of thin, flexible muscle that holds urine in the body.

Bone Scan

A scan to help show if cancer has reached the bones. If prostate cancer spreads to distant sites, it often goes to the bones first.

Bone-Targeted Therapy

Treatments to help strengthen the bones, to keep bones healthy and to decrease the number of skeletal-related events.

Chemotherapy

The use of medications to kill prostate cancer cells that have spread throughout the body.

CT Scan

X-rays and computer calculations used to see and measure internal tissue and organs.

Digital Rectal Exam (DRE)

The insertion of a gloved, lubricated finger into the rectum to feel the prostate and check for anything abnormal.

Ejaculation

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

Erectile Dysfunction (ED)

Problems getting or keeping an erection.

Genetic Counselor

Experts who conduct and explain genetic testing results.

Genetic Tests

Tests used to look for DNA passed down from one generation to the next. Here, experts are looking for inherited mutations that can predispose to cancer.

Genomic Tests

Tests to look for acquired mutations that occur randomly to study all of a person’s genes (the genome). The results may help see how DNA and genes work within a cell and may suggest a path to better treating your cancer.

Germline Tests

This testing looks for DNA passed down from one generation to the next. Here, experts are looking for inherited mutations that can predispose to cancer.

Gleason Score

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

Hormone Therapy

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

Immunotherapy

A treatment that boosts the ability of the immune system to fight prostate cancer.

Incontinence

Loss of bladder control. This may be about urine leakage (urinary) or loss of control with stool (fecal).

Lymph Nodes

Rounded masses of tissue found throughout the body that produce cells to fight invading germs or cancer.

Metastatic

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

MRI Scan

Radio waves and a strong magnetic field used to make highly detailed pictures of organs and tissue in the body.

Oncologist

A doctor specializing in the treatment of cancer.

Orchiectomy

Surgery to remove the testicles.

Palliative Care

Medical care to provide relief from pain and other symptoms of a serious illness.

PARP Inhibitor

A medical treatment to stop the PARP enzyme from repairing cancer cells, causing the cells to die, making the treatment more effective.

Pathologist

An expert who identifies diseases by studying cells and tissues under a microscope.

Pelvis

The lower part of the abdomen, between the hip bones.

Penis

The male genital organ.

PET Scan

A special drug (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. The scanner allows to better see where and how much the cancer is growing.

Precision (Personalized) Medicine

A tailored approach to care based on the genes, proteins, and other substances in a person’s body. Tailored (targeted) therapies may be an option to treat your illness.

Prostate

A walnut-shaped gland below the bladder that surrounds the urethra. The prostate makes fluid that goes into semen.

Prostate-Specific Antigen (PSA)

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.

PSA Doubling Time (PSADT)

This is the number of months required for the PSA value to increase two-fold.

Radiation

Two options for prostate cancer treatment include brachytherapy (small radioactive “seeds” implanted in the prostate) and external beam radiation (rays targeted at the tumor from outside the body).

Radiopharmaceuticals

Drugs with radioactivity that can target radiation to the exact areas in the bones where cancer cells are growing.

Rectum

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

Recurrence

The return of cancer after treatment in the same location or another part of the body.

Semen

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

Seminal Vesicles

Glands that help produce semen.

Somatic Tests

This type of testing looks at DNA that is not passed down from your parents, but rather DNA changes that have happened in the tumor. This type of acquired mutation does not impact the health of your family, but could help with your own treatment choices and may help your health care team diagnose, watch and treat your cancer.

Sperm

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

Testicles

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

Tissue

Group of cells, similar in form and function, within an organism.

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. Extends from the bladder to the tip of the penis.

Urinary Tract

Includes organs that take waste from the blood and carry it out of the body.

Urine

A liquid, often yellow in color and made by the kidneys, which contains waste and water.

Urologist

A doctor who specializes in the diagnosis and treatment of problems linked to the urinary tract and nearby pelvic structures.

X-ray

A test that uses radiation to make pictures of the tissues, bones and organs inside the body.

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.

For more information, visit **UrologyHealth.org/UrologicConditions**.

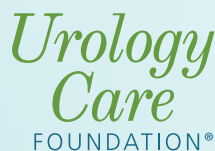
Disclaimer

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.

Developed in collaboration with:



This patient guide is also available in Spanish. • Esta guía para el paciente también está disponible en español.



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