

So you're newly diagnosed with prostate cancer...



We're here to help.

# We're here to help.

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## You've Been Diagnosed With Prostate Cancer. Now What?

A prostate cancer diagnosis can be scary and overwhelming, but finding helpful resources to aid in your fight shouldn't be. We developed this guide for newly-diagnosed men and their families to help cut through the clutter and provide clear, easy to digest information about prostate cancer tailored for someone like you who is just beginning his journey.

This toolkit focuses on the basics of your prostate cancer diagnosis, treatment options, lifestyle changes, and support resources. We'll also share advice and words of wisdom from men who are fighting the disease or who've won their battles.

It's important to remain hopeful on your journey. Most prostate cancer is slow growing and more than 2.9 million American men are living with the disease today. Arm yourself with education and rally your support network. You aren't alone in your fight: ZERO is here to help.

Don't panic. Do your research. Seek out support – whether that might be with a support group or with your family or friend – continue to do your research, as the disease doesn't affect all men the same way.



Johnny Payne, prostate cancer survivor

## Prostate Cancer Basics

Now that you've been diagnosed with prostate cancer, it is very important that you arm yourself with education so that you can understand the disease you're fighting and make the most informed decisions about your treatment options. Prostate cancer is usually a very slow growing disease and once diagnosed there is time to gather information, consider your options, and make a plan.

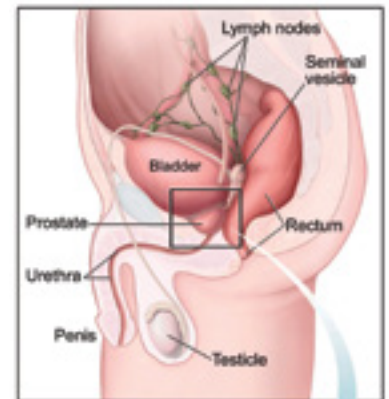
More than 50 percent of men newly diagnosed with prostate cancer have low-risk disease that will likely not spread beyond the prostate to cause harm, problems, or symptoms. However, some prostate cancers are aggressive and will spread to other parts of the body. There are more than 2.9 million prostate cancer survivors in the U.S. today. You have cause to hope for a long, healthy life.

### The Basics: What is my prostate?

The prostate is a walnut-shaped gland located below the bladder, behind the base of the penis, and in front of the rectum. It surrounds the upper part of the urethra, which is the tube that carries urine from the bladder. The prostate makes seminal fluid that protects, supports, and helps transport sperm.

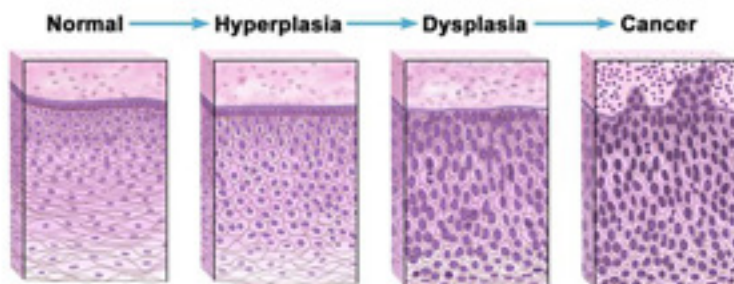
### The Basics: What is prostate cancer?

Normally, as cells grow old and die, new cells take their place. Prostate cancer is a disease in which normal cells in a man's prostate gland change and grow uncontrollably to form a tumor. Only men can develop prostate cancer because only men have a prostate gland. Prostate cancer is the most common type of cancer diagnosed in American men.



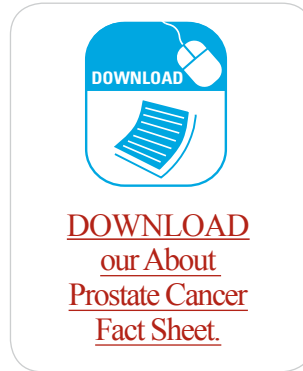
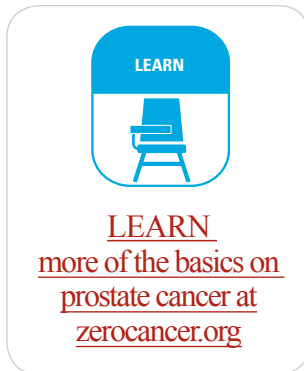
National Cancer Institute

### Normal Cells May Become Cancer Cells



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Drawing of four panels showing how normal cells may become cancer cells. The first panel shows normal cells. The second and third panels show abnormal cell changes called hyperplasia and dysplasia. The fourth panel shows cancer cells.



### The Basics: Statistics and Risk Factors

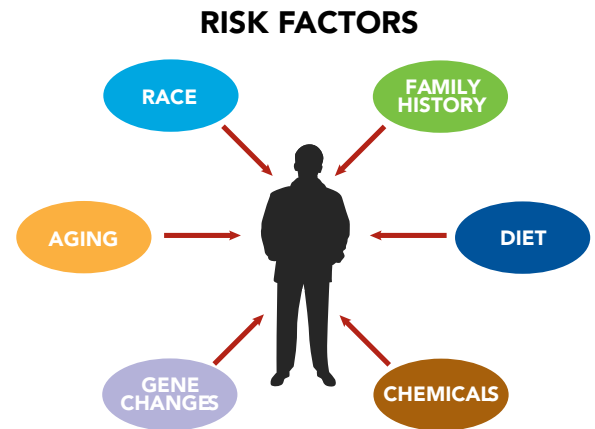
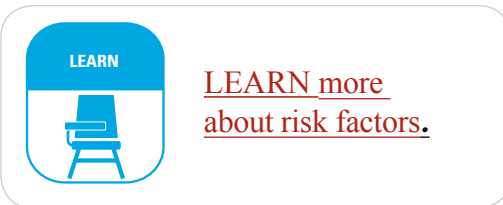
Now that you've been diagnosed with prostate cancer, you may want to familiarize yourself with some statistics and risk factors about the disease. Knowing how many men are affected and what risk factors contribute to a prostate cancer diagnosis is one way to better understand what you're fighting.



- One in nine American men will have prostate cancer during his lifetime.
- Prostate cancer is the second leading cause of cancer death among American men and is the most commonly diagnosed.
- The American Cancer Society estimates in its Cancer Facts & Figures 2018 report that 164,690 men will be told they have prostate cancer in 2018 and 29,430 will die from the disease this year.
- The most recent research shows the five-year survival rate for all men with prostate cancer is nearly 100 percent.
- The relative 10-year survival rate is 98 percent, and 96 percent for 15 years.
- Currently there are nearly 2.9 million American men living with the disease – roughly equal to the population of Chicago.

All men are at risk of developing prostate cancer. Women are not at risk because they do not have a prostate. The greatest risk factors for developing the disease are increasing age, family history, ethnicity, and diet. If any of the following describe you, you are at increased risk for prostate cancer.

- I am older than 50
- I have a family history of prostate cancer
- I am African-American



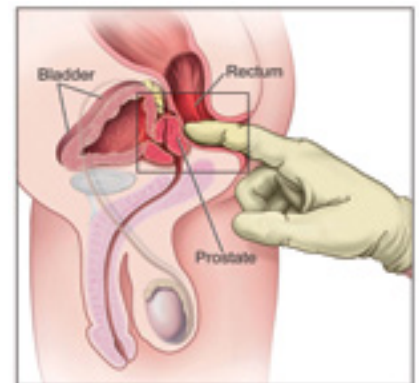
## How is Prostate Cancer Diagnosed?

If you're reading this guide, you likely have been diagnosed with prostate cancer. Prostate cancer is diagnosed using a number of tests described below. You likely have already had some of these, but you may need further tests to find out whether the cancer has spread and how aggressive it is. You may not need to have all of these tests, and you might not have them in this order.

**PSA Test** – The PSA Test is a blood test that measures the amount of prostate specific antigen (PSA) in your blood. PSA is a protein produced by normal cells in your prostate and also by prostate cancer cells. It's normal to have a small amount of PSA in your blood, and the amount rises as you get older.

**Digital Rectal Examination (DRE)** – During a Digital Rectal Examination (DRE) a doctor or nurse feels your prostate through the wall of the back passage (rectum) to check for any lumps or hard areas and to get an idea of its size. They'll wear gloves and put some lubricant onto their finger to make it more comfortable.

**Prostate Biopsy** – A biopsy involves using thin needles to take small pieces of tissue from the prostate. The tissue is then looked at under a microscope to check for cancer. Cancer can only be diagnosed with a tissue sample.



## NEW TESTING OPTIONS

Recent research has yielded additional tests that can give you and your medical team more information to help determine the probability of both finding cancer during a biopsy and determining how aggressive that cancer is likely to be.

**4Kscore** – 4Kscore is a blood test providing patient-specific probability of finding an aggressive form of prostate cancer during a biopsy. Doctors and patients can then make an informed decision on whether to have a biopsy. The test measures total PSA, free PSA, Intact PSA, and for certain enzymes called kallikrein. An algorithm used with the patient’s age and physical exam gives a probability percentage of having aggressive disease.

**AR-V7** – The blood-based test detects the V7 variant of the androgen receptor protein (AR-V7) in the nucleus of circulating tumor cells (CTC) — information that can help guide treatment selection in patients with metastatic castration-resistant prostate cancer.

**Axumin** – A molecular imaging agent indicated for use in PET imaging to identify suspected sites of prostate cancer recurrence in men who have elevated blood levels of PSA following prior treatment.

**ConfirmMDx** – The ConfirmMDx test addresses false-negative biopsy concerns to prevent undergoing unnecessary repeat biopsies and screening procedures and help reduce complications for patients. A specimen from the biopsy is required in order to benefit from this test.

**EPI** – The EPI test is a completely non-invasive, urine-based test to help rule out high-grade prostate cancer.

**Know Error** – The Know Error<sup>®</sup> system utilizes bar coding and forensic principles testing to confirm that surgical biopsy samples being evaluated belong exclusively to the patient being diagnosed and further confirm tissue specimens are free from contamination which can otherwise confound test results.

**PCA3** – PCA3 is a urine test that more accurately detects the possibility of prostate cancer by examining the expression of PCA3 – a gene specific to prostate cancer. The PCA3 score is used to determine the need for repeated biopsies. Research has continued for years to look into whether PCA3 can replace or serve as a substitute for the PSA test

**Phi** – The Prostate Health Index combines three blood tests that give a more accurate “Phi Score,” which gives information based on a high PSA to better determine the probability of finding cancer during a biopsy.

**ProMark** – ProMark is a protein-based prognostic test for prostate cancer used to help predict disease aggressiveness in early stage patients with biopsy Gleason Scores of 3+3 and 3+4.

## ADDITIONAL TESTING

Once your doctor has confirmed that you have prostate cancer, several other tests and procedures can be used to determine more about the location and/or severity of your cancer.

Tests that your doctor may recommend include MRI, PET, CT scans, and ultrasounds. These and other tests help physicians have a clearer picture of your disease so the best course of treatment can be recommended for you.

**A transrectal or transurethral biopsy** – A procedure to remove cells, fluid, or tiny tissue samples from the prostate for viewing under a microscope by a pathologist. The pathologist will check the tissue sample to see if there are cancer cells, and then determine the Gleason score

**Bone Scan** – A bone scan can show whether any cancer cells have spread to your bones. A small amount of a safe, radioactive dye is injected into a vein in your arm before you have the scan. If there is any cancer in the bones, the dye will collect in these areas and show up on the scan.

**CT Scan** – A CT (computerized tomography) scan can show whether the cancer has spread outside the prostate, for instance to the lymph nodes or nearby bones.

**MRI Scan** – An MRI (magnetic resonance imaging) scan uses magnets to create a detailed picture of your prostate and the surrounding tissues. You might have an MRI scan to find out if your cancer has spread. In some hospitals you might have an MRI scan before a biopsy. This can help your doctor see if there is any cancer in your prostate and where it might be.

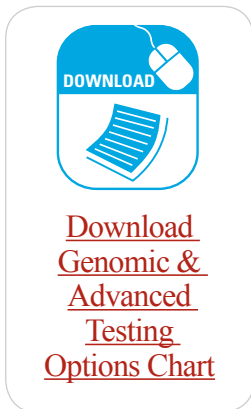
**Pelvic lymphadenectomy** – This is a procedure performed during the time of surgery to remove the lymph nodes in the pelvis. The lymph nodes are then examined under a microscope to see if they contain cancer.

**PET Scan** – A PET (positron emission tomography) scan shows how well different parts of your body are working. It can be used to check if cancer has spread outside the prostate. It is normally used to see if your cancer has come back after treatment.

**Transrectal ultrasound** – A procedure in which a small probe, about the size of a finger, is inserted into the rectum to check the prostate. The probe is used to bounce high-energy sound waves (ultrasound) off internal tissues or organs, which create a picture of echoes (called a sonogram). A transrectal ultrasound may be used during a biopsy procedure.



One of the challenges in facing a prostate cancer diagnosis is knowing which diagnostics make the most sense for you. The goal of advanced testing is to provide you and your health care team with more information to create the best treatment plan for you. To help you navigate the options, here is an overview of what is currently available.



**ZERO - THE END OF PROSTATE CANCER**

## GENOMIC & ADVANCED TESTING OPTIONS FOR PROSTATE CANCER

Every man's prostate cancer journey is different. Determining who needs treatment for prostate cancer has evolved with new options to diagnose aggressive versus indolent disease. Select the "phase" of the journey you're in now, or see what you may need to do in the future to ensure you have the best treatment plan in place.

### IF I NEED TO GET TESTED

<b>PSA</b> Blood test to check levels of prostate-specific antigen	<b>SelectMDx</b> Helps identify risk of aggressive disease	<b>PHI</b> Three tests of a blood sample to determine your prostate health score	<b>4Kscore</b> Helps your health care team decide whether you need a biopsy
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### IF MY BIOPSY NEEDS MORE INFORMATION

<b>ConfirmMDx</b> DNA test to confirm negative biopsy results	<b>PCA3</b> Determines if elevated PSA is caused by prostate cancer	<b>4Kscore</b> Helps your health care team decide whether you need a biopsy	<b>Know Error</b> DNA testing to ensure that biopsy samples are free from contamination
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### IF MY BIOPSY IS POSITIVE FOR CANCER

<b>OncotypeDx</b> Genomic assay that analyzes prostate cancer gene activity	<b>Prolaris</b> Measures how aggressive your prostate cancer is	<b>P10</b> Predicts likelihood of recurrence or metastasis	<b>ProMark</b> Generates a personalized score for how aggressive your cancer may be	<b>Know Error</b> DNA testing to ensure that biopsy samples are free from contamination
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### IF I NEED SUPPORT AFTER SURGERY

<b>Prolaris</b> Measures how aggressive your prostate cancer is	<b>Decipher</b> Predicts likelihood of metastasis after surgery	<b>AR-V7</b> Guides treatment selection in patients with metastatic castration-resistant prostate cancer
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### IF WE'RE MONITORING MY DISEASE

<b>PSA</b> Blood test to check levels of prostate-specific antigen	<b>Testosterone</b> Better informs PSA results and indicates how treatment is progressing	<b>Axumin</b> Used in PET imaging to identify suspected sites of prostate cancer recurrence in men with elevated PSA
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**Molecular Profiling** – Molecular profiling can help doctors better understand your tumor’s gene mutations, which could unlock treatment opportunities. Your medical team may be able to craft an individualized treatment plan of targeted therapies and clinical trials based on your specific molecular profile.

Through **ZERO’s Decode Your Prostate Cancer** program, eligible patients with metastatic prostate cancer can access their molecular profiles for free and receive a tailored plan of care based on the mutations driving their cancers. This program is provided in partnership with Perthera, a leading company in precision medicine.

## Understanding Your Prostate Cancer

### Your Test Results

Test results will help you get a clearer picture of your prostate cancer. You’ll want to get familiar with the terms stage, grade, and risk group – all terms that your doctor will use to classify your prostate cancer and determine the best treatment options for you.

### Stage

Staging prostate cancer determines if and how far the prostate cancer has spread beyond the prostate. There are four stages of prostate cancer: I through IV. You might have an MRI, CT, or bone scan to determine the stage of your cancer. The results should help you and your doctor decide which treatments might be suitable for you. You might not need a CT or bone scan if your PSA is low and your biopsy results suggest that the cancer is unlikely to have spread.



**LEARN**  
[more about how prostate cancer is diagnosed in our video Early Detection of Prostate Cancer](#)



**LEARN**  
[more and enroll in the Decode Your Prostate Cancer program](#)

PROSTATE CANCER STAGES	
<b>Stage I</b>	- the cancer is small and only in the prostate
<b>Stage II</b>	- the cancer is larger and may be in both lobes of the prostate but is still confined to the prostate
<b>Stage III</b>	- the cancer has spread beyond the prostate to close by lymph glands or seminal vesicles
<b>Stage IV</b>	- the cancer has spread to other organs such as the bone and is referred to as metastatic cancer. If prostate cancer spreads, or metastasizes, to the bone, you have prostate cancer cells in the bone, not bone cancer

For a detailed description of each stage, see the information at the bottom of the page. Detailed Staging, adapted from www.cancer.gov.

GLEASON SCORES IN CATEGORICAL ORDER	
<b>Gleason X</b>	Gleason score cannot be determined
<b>Gleason 6 or less</b>	The tumor tissue is well differentiated, less aggressive and likely to grow more slowly
<b>Gleason 7</b>	The tumor tissue is moderately differentiated, moderately aggressive and likely to grow but may not spread quickly
<b>Gleason 8-10</b>	The tumor tissue is poorly differentiated or undifferentiated, highly aggressive and likely to grow faster and spread

**Grade**

Your prostate cancer’s grade, referred to as the Gleason score, indicates how likely it is that the tumor will spread, and is a good indicator of the aggressiveness of your disease. Your Gleason score is worked out by adding together two Gleason grades. The first is the most common grade in all the samples. The second is the highest grade of what’s left. When these two grades are added together, the total is called the Gleason score.

Gleason scores range from 2 to 10. The higher the number the more abnormal the prostate tissue is compared to normal tissue. The two numbers are then added to get a score. Higher Gleason scores mean the cancer is more likely to spread. Today almost all men have a Gleason score of 6 or above.

**D’amico Risk Group Classification System**

The D’amico risk group classification system was developed to estimate the likelihood of recurrence for any patient using a given set of parameters and is widely used as one of many individualized risk assessment tools. This analysis could help those battling prostate cancer to make a more informed decision regarding their treatment.

D’AMICO RISK GROUP CLASSIFICATION SYSTEM		
<p><b>First, it’s important to gather your numbers:</b></p> <ul style="list-style-type: none"> <li>• <b>PSA:</b> You will need the results of your PSA test, a blood test that detects prostate-specific antigen – a protein produced by the cells in your prostate.</li> <li>• <b>Gleason score:</b> The results of your Gleason score, given based on the microscopic appearance of your cancer cells.</li> <li>• <b>Clinical stage T score:</b> And your T stage, the size of your tumor as seen on an ultrasound or during a rectal exam.</li> </ul>		
<p><b>Using these numbers, your risk is either categorized as:</b></p>		
<ul style="list-style-type: none"> <li>• <b>Low risk:</b> Those with a PSA &lt; than or = to 10, a Gleason score &lt; than or = to 6, or are in clinical stage T1-2a</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Intermediate risk:</b> Men with a PSA between 10 and 20, a Gleason score of 7, or are in clinical stage T2b</li> </ul>	<ul style="list-style-type: none"> <li>• <b>High-risk:</b> Those with a PSA of more than 20, a Gleason score = or &gt; than 8, or are in clinical stage T2c-3a.</li> </ul>

**Risk Group**

The risk group provides information about how likely it is that the cancer will come back (if it is early stage) or progress. There are several new, genomic tests available that go beyond the standard risk-assessment done with the PSA and Gleason score. These tests help to predict if the cancer will spread beyond the prostate, if it is aggressive, or how likely it is to return. Talk to your doctor to find out if you are a candidate for one of these tests before making a treatment decision.

### **Genomic Testing**

There are several new, genomic tests available that go beyond the standard risk-assessment done with the PSA and Gleason score. These tests help to predict if the cancer will spread beyond the prostate, if it is aggressive, or how likely it is to return. Genomic tests are useful for helping men and their physicians decide on a strategy for managing treatment, so they are often most helpful for men newly diagnosed with prostate cancer that is still confined to the prostate. However, men who have had a surgery and want to understand their risk of five-year recurrence may also find certain tests helpful. Talk to your doctor to find out if you are a candidate for one of these tests before making a treatment decision.

### **Decipher**

Decipher Biopsy is available for patients diagnosed with localized prostate cancer at the time of biopsy. This test can help men and their doctors determine if it may be safe to consider active surveillance, treatment, or a combination of therapies. No additional procedure for the patient is needed to run this test.

Decipher Post-Op predicts the likelihood of prostate cancer metastasis for men with adverse pathology after radical prostatectomy. This test can help patients and their doctors decide if additional treatment is needed after surgery. Decipher Post-Op uses a tissue sample that was removed during surgery, so no additional procedure for the patient is needed.

### **Oncotype Dx**

Oncotype Dx test looks at the activity of certain genes in the prostate tumor and assigns a personalized result, called the Genomic Prostate Score, to each case. This number predicts the chance that the disease will be more aggressive and spread to other parts of the body if left untreated. This is used after a confirmed prostate cancer diagnosis of low risk disease and uses biopsy tissue to predict likelihood of future growth and spread. It is helpful for those considering active surveillance.

### **Prolaris**

The Prolaris test measures how fast your cancer cells are dividing to predict aggressiveness. This is used after a confirmed prostate cancer diagnosis of low risk disease and can use both biopsy tissue and tissue from a radical prostatectomy to predict likelihood of metastasis, biochemical recurrence, and death from prostate cancer. It is helpful for men deciding on a treatment option or trying to decide on additional treatment after surgery.

### **ProstaVysion**

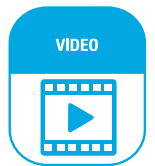
ProstaVysion test looks at a sequence of certain genes and provides a personalized genetic panel to determine aggressiveness. This is used after a confirmed prostate cancer diagnosis and uses biopsy tissue to predict likelihood of future growth and spread. It is helpful for those considering active surveillance.



[WATCH  
our webinar  
Genomic Testing and  
Demystifying your  
Diagnosis.](#)



[WATCH  
our webinar  
Understanding  
Prostate Cancer  
in the Age of  
Personalized  
Medicine.](#)



[WATCH  
this video on  
Genomic Testing](#)

### Before You Choose Your Treatment Plan

Treatment options vary depending on prostate cancer stage and grade. Before making a treatment decision:

- Consider a second opinion.
- Make sure to include a visit to an oncologist to know all of your options.
- Consider genomic testing to learn how aggressive your cancer is and how likely it is to recur.
- Ask your doctor: Is my prostate cancer a pussycat or a tiger?

### Kitty Cat or Tiger: Types of Prostate Cancer

If your prostate cancer is a kitty cat that means that there is a very low risk of the disease spreading beyond your prostate anytime soon. If your prostate cancer is a tiger, that means there is a very high risk of the disease being aggressive and spreading beyond your prostate.

Researchers have developed the Circulating Tumor Cell Test to help distinguish advanced disease. Circulating Tumors Cells or CTCs circulate in the blood stream after breaking off from the primary tumor. CTCs can take root in other parts of the body and form additional tumors (metastasis). The test helps detect any measurable CTC circulation and help determine advanced disease.

Remember, the more information you and your doctor have about your actual cancer, the better armed you are to fight the disease with the right tools.

### Genomics vs. Genetics

Genomics is the study of all the genes in the genome and their interactions with the environment. This is related to but not the same as genetics, the study of individual genes and inherited traits from one generation to the next.

The study of genetics in prostate cancer is important because family predisposition may be responsible for 5-10% of all prostate cancers. A family history increases a man's risk for prostate cancer by 60%.

Genomics in prostate cancer looks at how certain sets of genes in the prostate cancer tumor interact and function. The activity of these genes can then influence the behavior of the tumor, including how rapidly it is likely to grow and spread.

#### **GENOMICS vs. GENETICS**

- Genetics is the study of inherited traits and genes
- Genomics is the study of how a set of genes behave

### Choosing Your Health Care Team and Treatment Plan

Most likely treatment will begin shortly after diagnosis, but you have time to gather facts and information. The stage and grade of your tumor will impact what treatment options are available to you. Every treatment has pros and cons and will involve a different team of health care professionals.

Before you decide on a treatment, ask yourself:

- Do I need treatment?  
*Many men have slow-growing cancers that do not need immediate treatment or even at all.*
- Have I found a second opinion?  
*Getting a different point of view from a different specialty can help.*
- What are my priorities?  
*Saving money, reducing side effects, and preventing recurrence are all considerations.*

To receive the best care possible for prostate cancer, seek care from a multidisciplinary medical team, a group of health care professionals from different specialties that work together to suggest a treatment plan for you based on your diagnosis, personal health, and preferences. This approach will ensure you have the best health outcome and highest quality of life.



[WATCH this video to learn more about choosing a multidisciplinary team.](#)

I tell men to research as much as you can and let your doctor know your questions and concerns.

Stephan Casper, prostate cancer patient who did his own research through [www.zerocancer.org](http://www.zerocancer.org).



## Choosing Your Health Care Team

It is likely that throughout your prostate cancer journey, you will work with several medical specialists for treatment. Keep in mind that you have a choice in who manages your care. This is about finding the right treatment team to work with to make the right decisions for you. Make sure to find a team you are comfortable with and trust.

Your team may consist of a combination of the following medical professionals:

### **Urologist**

A urologist is a physician specializing in diseases of the male reproductive organs and male and female urinary tract. Some urologists have oncology training. Many urologists are also involved in certain aspects of other forms of therapy including radiation therapy, hormonal therapy, treatment of advanced disease, clinical trials, and active surveillance. All urologists are surgeons as well, and many perform prostate cancer surgery.

### **Radiation Oncologist**

A radiation oncologist is a highly trained physician specializing in the treatment of prostate cancer using the various types of radiation approved to treat the disease.

### **Medical Oncologist**

A medical oncologist is a physician who specializes in the non-surgical treatment of cancer with medicines such as chemotherapy, hormonal therapy, and other drugs. While many men with prostate cancer will work most closely with a urologist, it is important to include a medical oncologist in the early phases of treatment planning.

### **Primary Care Physician**

This is a man's personal physician, most likely an internist or family medicine physician who treats common illness and oversees general care.

### **Oncology Social Worker**

Oncology social workers are trained to work with prostate cancer patients and their families, most frequently, men with advanced prostate cancer. It is important to understand your emotional well being and get the support you need mentally as well as physically. An oncology social worker provides individual counseling, access to support groups, and referrals to related services for men with prostate cancer.

## QUESTIONS FOR THE DOC



- What is the stage and grade of my prostate cancer?
- What other tests will be done?
- What are my treatment options? What do you recommend for me? Why?
- What are the potential side effects of each treatment you recommend?
- How can these side effects be managed?
- What can I do to prepare for treatment?

**Physical Therapist**

A physical therapist can help deal with the physical changes caused by cancer treatment. Before or after surgery or radiation therapy, working with a physical therapist to strengthen the pelvic floor can help to manage or prevent side effects such as urinary incontinence.

**Nutritionist**

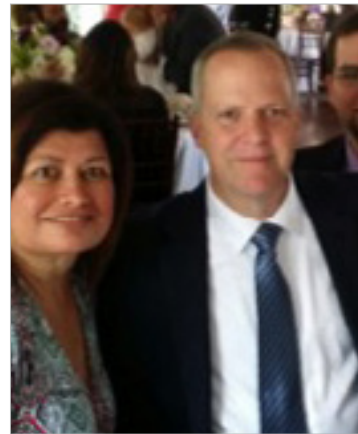
A nutritionist provides information and guidance about good nutrition. This can help a patient combat cancer- or treatment-related weight loss or gain by recommending foods that provide adequate calories, vitamins, and protein. In addition, a nutritionist provides helpful tips and recipes customized to fit your specific dietary needs.

**Navigator**

The patient navigator is an expert in understanding the details of cancer treatment and will support, inform, guide, and answer questions for you through all stages of treatment and beyond. As advocates for patients and their families during prostate cancer treatment, they enhance the quality of care you receive. If a patient navigator is not made available to you, ZERO can help with our [ZERO360](#) program described later in this toolkit.

When I found out how aggressive my prostate cancer was, I wanted to be as aggressive to it as it was to me.

Malcolm Carmine, prostate cancer patient fighting his advanced disease with chemotherapy and hormone therapy





## Treatment Options

The treatment of prostate cancer depends on many factors including the size and location of the tumor, the aggressiveness of the tumor, whether the cancer has spread, and your overall health. Treatment is also a very personal decision and what is right for one man may not be right for another. There are many treatment options for men with prostate cancer. Learn about the treatment options that are available to you, ask many questions, and then consider what you want for yourself and your life.



[WATCH the webinar Treatment Options for Localized Prostate Cancer](#)

### **Active Surveillance**

Active Surveillance is only done in men who would otherwise be eligible for treatment, and is “active” by definition and requires routine follow-up, exams, labs, and biopsies.

### **Watchful Waiting**

Watchful Waiting is literally waiting for symptoms to show up in men who have other competing comorbidity or advanced age precluding them from initial treatment.

### **Surgery**

A prostatectomy is the removal of the prostate gland by surgery. The goal is to remove all of the cancer from your body. There are several types of prostatectomy.

### **Radiation Therapy**

Radiation therapy uses high-energy rays to target the prostate and any surrounding areas with cancer or at risk of cancer.

### **Cryotherapy**

Cryotherapy for prostate cancer freezes prostate tissue, causing cancer cells to die. This type of treatment is sometimes used as an alternative to surgical removal of the prostate gland.

### **Hormone Therapy**

Prostate cancer is fueled by male hormones, which are called androgens. The primary male androgen is testosterone. Hormone therapy, also called androgen deprivation therapy, or ADT, stops your body from making testosterone to stop or shrink the tumor. In addition, if a patient has undergone hormone therapy to treat his prostate cancer, his doctor can perform a testosterone test to monitor this hormone as way of helping to determine if treatment is effective.

### ***Immunotherapy***

Immunotherapy uses a man's own immune cells to attack advanced prostate cancer. The cells are taken from the man with prostate cancer, activated to fight, and returned to the man.

### ***Chemotherapy***

Chemotherapy is the use of intravenous or oral drugs to kill cancer cells and prevent them from multiplying. Chemotherapy stops new cancer cells from being made.

### ***Ultrasound***

High Intensity Focused Ultrasound is a treatment currently in testing. It destroys the cancer by using sound waves on the prostate tumor.

### ***Metastatic Disease***

There are several treatment options available to men who have cancer that has moved beyond the prostate to the lymph nodes, other organs, or the bones.

***CyberKnife*** CyberKnife is a non-invasive treatment radiation therapy for prostate cancer that uses a robotic design, coupled with real-time imaging to deliver a maximum dose of radiation directly to the tumor.

### ***Brachytherapy***

Brachytherapy involves implanting small, permanent radioactive seeds or temporary needles into the cancerous prostate. After you are identified as a good candidate for brachytherapy, an ultrasound is used to guide the placement of needles into the prostate. Depending on whether you and your doctor have chosen permanent/low-dose brachytherapy or temporary/high-dose brachytherapy, these needles are then used to either put in permanent seeds or temporary radiation sources. Placement of seeds is a minimally invasive procedure and does not require incisions. Men undergoing the procedure can return to full activity in less than a week. This is done as an outpatient procedure before you begin treatment.

### ***Androgen Deprivation Therapy (ADT)***

ADT or hormone therapy is used to lower androgen levels or stop them from getting into prostate cancer cells. It can make prostate cancers shrink or grow more slowly for a time and is often used in combination with other treatments.

**Radium-223**

Radium-223 (Xofigo) is a drug used to treat advanced prostate cancer, specifically in men whose cancer has spread or metastasized to their bones after surgery or other treatments to lower testosterone. Radium-223 is injected into a vein once a month for a total of six doses. It works by using radioactive particles to mimic calcium and targeting cancer in the bones. The drug binds with minerals in the bone to deliver radiation directly to bone tumors, limiting the damage to the surrounding normal tissues. The exact dose and schedule of radium depends on your size, among other factors.



[LEARN](#) more about advanced disease.



[WATCH](#) our webinar on [Current Treatment in Advanced Prostate Cancer: Side Effect Management and Clinical Trials.](#)

After I was diagnosed with prostate cancer, I vowed to not allow the disease or complications from the surgery to keep me away from living my life to the fullest. And I haven't.


David Pieper, prostate cancer survivor who has completed over 50 triathalons and an Ironman since treatment.



**Side Effects**

There are side effects from each treatment for prostate cancer. Just as prostate cancer varies from man to man, so will the side effects each man experiences. Your health care team will work hard to ensure you will experience minimal side effects as a result of treatment.

The most common side effects of treatment are urinary incontinence (the inability to control your bladder) and erectile dysfunction (the inability to achieve a full erection). Other side effects can include fatigue, depression, and infertility. It is important to talk to your doctor and your partner about all potential side effects before choosing treatment as these potential changes can impact your self-esteem and personal relationships. Once you determine your treatment, work with your doctor on a plan to manage any side effects you experience.



**WATCH**  
[this video on managing common prostate cancer side effects.](#)

**MANAGING SIDE EFFECTS**

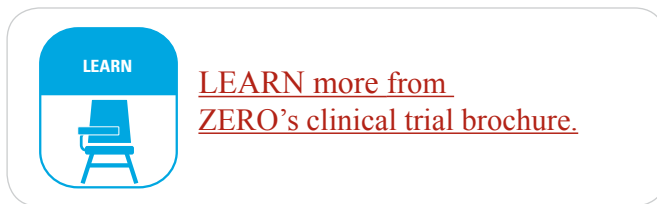
TREATMENT	WHAT IT DOES	POSSIBLE SIDE EFFECTS
Surgery	Removes the cancerous tissues and the prostate	Urinary incontinence, erectile dysfunction (ED), and infertility
Hormone Therapy	Minimizes presence of androgens which fuel prostate cancer growth	Erectile dysfunction (ED), hot flashes, bone loss, and cardio-vascular events
Radiation	Slows prostate cancer cell growth by targeting cells externally or by injection	ED, incontinence, diarrhea, rectal bleeding and discomfort during urination and bowel movement
Immunotherapy	Changes the body's immune system to kill cancer cells	Fever, chills, fatigue, and joint or body ache
Bone-related Treatments	Inhibits bone loss and fractures and relieves pain from prostate cancer in the bone	Low grade fever, tingling around mouth or hand cramps from low calcium, dental pains
Chemotherapy	Targets cancer cells that grow quickly including cancer cells metastasized to the bone	Hair loss, fragile bones, nausea and nervous system disorders like confusion, depression, or headaches

## Research and Clinical Trials

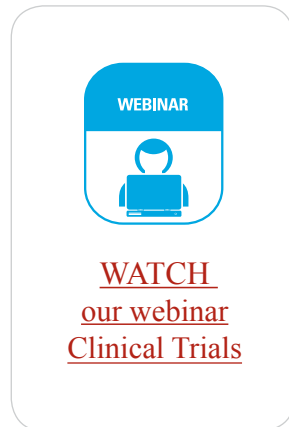
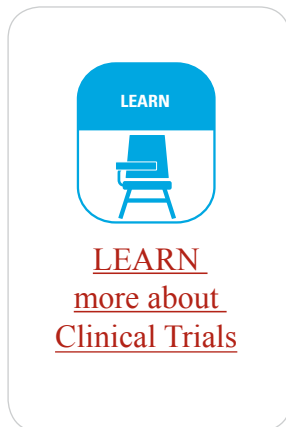
ZERO is committed to ending prostate cancer by supporting the most impactful bench to bedside research breakthroughs. As the leading organization that protects and grows prostate cancer research funding, ZERO has helped discover nearly half of all advanced treatments for prostate cancer. There are several potential new treatments and diagnosis tools in the pipeline now. We continue to fight for more options for men and their families to help support the significant amount of talent and attention focused on ending prostate cancer.

### **Clinical Trials**

After consulting with your doctor, you may consider enrolling in a clinical trial to gain access to experimental therapies or techniques that are still in the investigational stage. A clinical trial is a research study investigating experimental treatment to see if it is safe to use and effective in fighting a disease. Most treatments used today for prostate cancer are the results of past clinical trials.



Many times people do not participate in a clinical trial because they did not know they were eligible or that one is available, so be sure to ask your doctor when making your treatment decisions. Participating in a clinical trial is a way to gain access to promising, and perhaps effective, drugs yet to be approved by the FDA. Hundreds of research projects are currently investigating the potential of new drugs and new combinations of drugs.



### Monitoring for Recurrence

The completion of prostate cancer treatment can bring both relief and worry. When caught early, your initial treatment may mean you are cured. Most men will live cancer free for years, possibly forever. But you may also feel worried, anxious, or fearful that your cancer may come back.

Up to 40 percent of men will experience a recurrence, so it is important to understand your risk as well as live your life after cancer. Cancer recurrence is the return of cancer after a period when no cancer cells could be detected in the body. You should continue regular PSA testing to monitor your health.

When PSA levels rise to a certain threshold after prostate cancer treatment, this is known as biochemical recurrence. This means that some cancer cells have survived and are producing PSA. If this happens, the doctor will order additional tests and make recommendations for how to manage your disease.



[LEARN](#)  
[tips for coping](#)  
[with](#)  
[recurrence](#)



[WATCH](#)  
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[WATCH](#)  
[our webinar](#)  
[Survivorship:](#)  
[Living Beyond](#)  
[Prostate Cancer](#)

I still check in with my doctors every year. I love it when they say, 'Your PSA is below detectable level.' Increased awareness and early detection is so important for men, especially those with a family history like I had.



Austin Six,  
prostate cancer  
survivor

## Nutrition and Exercise

For many men, the diagnosis and treatment of cancer brings to their attention the need to change their diet and exercise behaviors. Maintaining a healthy diet and exercise regime can help you prepare for and recover after cancer treatment. It may also help to prevent the prostate cancer from coming back.

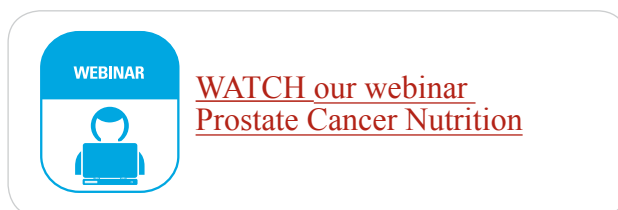
Some of the treatment options for prostate cancer, such as androgen deprivation therapy, can result in weight gain and bone loss. Depression and fatigue, which are common lingering effects of prostate cancer, can make it hard for even the most motivated man to exercise or eat healthy foods. Take small steps to take care of yourself and make a conscious choice to live a healthier life.

### ***Nutrition to Fight Prostate Cancer***

Although there is no diet to prevent or cure prostate cancer, you can make healthy choices that will help you fight your disease. Watching your weight may reduce your risk of dying from prostate cancer. Recent studies have indicated that the risk of dying from prostate cancer is more than double in obese men diagnosed with the disease compared with men of normal weight at the time of diagnosis. Obese men with local or regional disease have been shown to have nearly four times the risk of their cancer spreading beyond the prostate or metastasizing.

### ***Tips for Nutrition During Cancer Treatment***

- Maintain a healthy weight. For many men, this means avoiding weight loss by getting enough calories on a daily basis. For men who are overweight and are obese, this may mean losing some weight. If you are trying to lose weight, it should be moderate, meaning only about a pound a week.
- Get essential nutrients the body needs, such as protein, carbohydrates, fiber, vitamins, minerals, phytonutrients, such as carotenoids, and water. Not only will your body function better, you will feel better.
- Be as active as you can, such as taking a daily walk. If you sit or sleep too much, you may lose muscle mass and increase your body fat, even if you are not gaining weight.



### **Nutrition After Cancer**

As it is for all aspects of the cancer journey, nutrition is very important for survivorship. Proper nutrition and a prostate-healthy diet can help survivors live longer, receive more enjoyment out of life, and feel more empowered about their choices.

Choosing to eat a diet filled with fresh fruits and vegetables and other unprocessed, low-fat foods will help you regain strength after prostate cancer treatment. Nutritious eating can also reduce the risk of heart disease, high blood pressure, obesity, and diabetes. In addition, recent research suggests that making healthy food choices in your survivorship may lower your risk of recurrence and help you live longer.

### **Exercise to Fight Prostate Cancer**

Physical activity and exercise are critical factors in prostate health for both fighting the disease and preventing recurrence. Physical activity is shown to improve your physical and emotional health. In addition, it can be important for managing your weight, maintaining muscle and bone strength, and helping with potential side effects of prostate cancer treatment.

Physical activity simply means movement of the body that uses energy. Walking, gardening, climbing the stairs, playing soccer or dancing the night away are all good examples of being active. For health benefits, physical activity should be moderate or vigorous intensity that makes you breathe harder and your heart beat faster such as running, bicycling, or swimming.

### **Benefits of Regular Exercise During and After Cancer Treatment**

The side effects of prostate cancer treatment can impact your quality of life. Walking at an easy pace for three hours a week, or at a brisk pace for 90 minutes, can alleviate some of the symptoms of prostate cancer treatment, such as fatigue, depression, and body weight.

Exercise can help to:

- Reduce anxiety and fatigue
- Improve self-esteem
- Increase feelings of optimism
- Improve heart health
- Maintain a healthy weight
- Boost muscle strength and endurance



[LEARN  
more about  
nutrition and  
prostate cancer.](#)



[LEARN  
more about  
exercise and  
prostate cancer.](#)



## Additional Resources and Downloadable Tools

Feeling frightened, isolated, or angry are normal and common reactions to learning you or someone you love has been diagnosed with cancer. Support exists to help you with all aspects of the journey. Don't be afraid to speak up and ask for help along the way. Take advantage of financial assistance, the advice of survivors, support groups, educational programs, and other resources, many free of charge.

Having a team behind me – including my medical team, and the helpful support group I attended – made it more manageable, made it something I can understand.

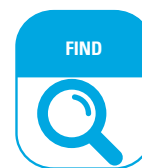
Miguel Buddle,  
prostate cancer patient



### **Prostate Cancer is a Family Disease**

Your prostate cancer diagnosis will not only affect you, but your entire family. You'll need a support system to help you cope emotionally and physically with your disease. For many reasons, it is very important to share your diagnosis with your family and friends. Bring your caregiver to your appointments with you and ask them to help you record information and make decisions. If you don't have a spouse, partner or family member that can fill a caregiver role, consider a close friend or reach out to a support group in your community.

In addition to the support your family can provide, knowing that prostate cancer runs in the family is very important information for your children, grandchildren, and extended family. Prostate cancer is a hereditary disease and men are two and a half times more likely to get the disease if their father or brother has had it, compared to someone who doesn't have any relatives who have been diagnosed with prostate cancer. By sharing your diagnosis and journey with your family, you're also sharing critical information that could impact their health in the future.



[FIND  
information  
for Caregivers  
here.](#)

My wife Linda and I have gone through this now for five plus years, and I couldn't have done it without her. She inspires me and I inspire her, we've been a team for more than 30 years. We do it together.



Ray Hoetger,  
prostate cancer patient



WATCH our webinar  
Prostate Cancer and  
Your Family Tree:  
Implications for Cancer Risk  
and Genetic Testing

When my brother was diagnosed with prostate cancer, I learned a very valuable lesson: life is precious. This experience brought that to light, and I'm not ready to lose him, so I'm in for the fight of his life.

Suzanne Schlernitzauer,  
caregiver for her brother  
with prostate cancer



”

When Bob Evensen’s father, grandfather, and two uncles were all diagnosed with prostate cancer, he knew that he had to be vigilant about his health. Though he had no symptoms to alert him to his condition, Bob was diagnosed at the young age of 39, just 60 days after his own father’s diagnosis. “I am a walking testament to early detection and the benefit of education and awareness.”

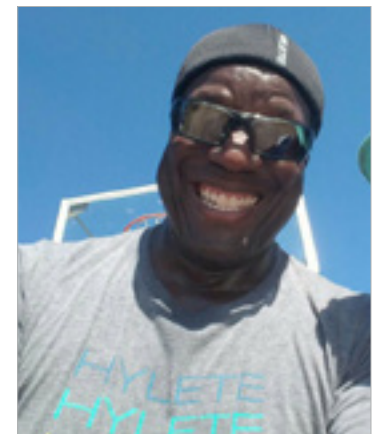


Bob Evensen and  
Father and Grandfather

“

Men dealing with a prostate cancer diagnosis: You are not alone! There are resources and support options all around, so please learn what you have to know. I have had others do the same for me, and I would not have gotten this far without them, not allowing me to give in, even in my really hard moments

”



Chas Rodgers,  
prostate cancer  
patient

“

### **ZERO360 for Financial and Emotional Support**

If you're feeling overwhelmed with the many decisions that come with a prostate cancer diagnosis, ZERO is here to help you. ZERO360 is a free, comprehensive patient support service to help patients and their families navigate insurance and financial obstacles to cover treatment and other critical needs associated with cancer.

Our team of experienced case managers is ready to help you and your family through your personal prostate cancer journey. To take advantage of this free service is easy. Contact us today by phone or online, so you and your loved ones can focus on your health.

Call 1-844-244-1309 Toll-Free or visit [www.zerocancer.org/zero360](http://www.zerocancer.org/zero360)  
Monday – Thursday 8:30 a.m. – 5:00 p.m. ET  
Friday 8:30 a.m. – 4:00 p.m. ET  
Closed on all major holidays



[WATCH our webinar Creating  
Generaton ZERO: Resources  
for Prostate Cancer](#)

### **MENtor: Peer Support**

ZERO has developed the MENtor Program to provide support to newly diagnosed men living with prostate cancer, as well as men who have experienced a recurrence. Ongoing support is a key factor for managing all health and this is particularly important in the face of a prostate cancer diagnosis. Peer to peer support from someone sharing similar experiences with a disease or condition has been shown to be a critical and effective strategy for sustained behavior change. It is an opportunity for shared experiences to improve quality of life. This support can take many forms, including face-to-face meetings, phone calls, and email and text communication.

Our trained, volunteer MENtors represent many different prostate cancer journeys and have a wealth of insights to share based on their experiences. To benefit from this peer support program, [please register here](#).

### **In Your Local Community**

ZERO is in your local community through our chapters program. We host a run/walk series across the nation in cities and small towns. Your local chapter is your jumping off point to get involved in advocacy efforts and to connect to your local prostate cancer community. You can meet other men and families like you who can provide support and camaraderie on your journey with prostate cancer. Find a [ZERO Prostate Cancer Run/Walk](#) near you!

### **ZERO's Website**

ZERO's website, [www.zerocancer.org](http://www.zerocancer.org), includes comprehensive educational and support information for men newly diagnosed with prostate cancer. You'll find videos, webinars, fact sheets, support resources, and inspirational stories from our ZERO's Heroes, others like you who are fighting prostate cancer. Here are a few tools that are especially helpful to newly diagnosed patients:

#### **Webinar and Video Library** ([www.zerocancer.org/learn/resources/webinars-videos](http://www.zerocancer.org/learn/resources/webinars-videos))

- Ongoing webinar series brings in experts to speak on a variety of topics.
- Past webinar topics include advanced prostate cancer, personalized medicine, bone health, nutrition, managing costs, and survivorship.
- All past webinars are recorded and archived on our website. Our webinars are great educational resources for patients who want the latest in-depth information from experts.
- Videos feature physicians, patients, and caregivers.
- Library contains more than 50 videos ranging from under one minute to twelve minutes in length and covering a wide range of topics. With our video library, patients can learn about prostate cancer directly from medical experts and fellow patients or caregivers.

#### **Fact Sheets and Tools** ([www.zerocancer.org/resources/fact-sheets-literature](http://www.zerocancer.org/resources/fact-sheets-literature))

- Printable and easy-to-understand fact sheets about different aspects of prostate cancer.
- Helpful tools for patients and caregivers.
- Reviewed by our medical advisory board.
- Fact sheet topics include [About Prostate Cancer, Newly Diagnosed, Early Stage Prostate Cancer, 10 Things Everyone Should Know About Prostate Cancer](#), and [10 Things African Americans Should Know About Prostate Cancer](#)
- Patient tools include our [Newly Diagnosed Worksheet](#), which helps patients keep track of their diagnosis; [Newly Diagnosed Questions to Ask](#), which helps patients talk to their doctor about their diagnosis and treatment options; and [Prostate Cancer Family Tree](#), which helps men understand their risk based on their family history.



**INFORMATION ABOUT YOUR PROSTATE CANCER**

Use this worksheet to keep track of basic information about your prostate cancer diagnosis as you need in order to make your decisions about your care.

Date of diagnosis \_\_\_\_\_

PSA level at diagnosis \_\_\_\_\_

Gleason score \_\_\_\_\_

Number of biopsy samples taken \_\_\_\_\_

Number of biopsy samples containing cancer \_\_\_\_\_

Stage at diagnosis (I-IV) \_\_\_\_\_

Nodal involvement?  Yes  No      Metastases?  Yes  No

My cancer is:  Localized (only in the prostate)

Locally advanced (spread to just outside the prostate)

Metastasized (spread to other organs or parts of the body) \_\_\_\_\_

Date	Follow-up Tests	Results:
_____	CT or CAT Scan _____	_____
_____	MRI _____	_____
_____	PET Scan _____	_____
_____	Other tests _____	_____

**PHYSICIANS**

Prostate Cancer Diagnosed by:

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Contact information: \_\_\_\_\_

Other doctors seen:

Name: \_\_\_\_\_ Contact information: \_\_\_\_\_

Name: \_\_\_\_\_ Contact information: \_\_\_\_\_

Other important numbers: \_\_\_\_\_

**LEARN MORE**

We encourage you to use this information in conversations with your health care team about prostate cancer and related topics. For more information about prostate cancer and ZERO – The End of Prostate Cancer, visit our website [www.zerocancer.org/learn](http://www.zerocancer.org/learn).

*ZERO - The End of Prostate Cancer provides this information as a service. It is not intended to take the place of medical professionals or the recommendations of your healthcare team. We strongly suggest consulting your healthcare team if you have questions about your specific care.*

## Prostate Cancer Terms

With so many things to comprehend at once, we often hear that newly diagnosed men are struggling to understand all the new vocabulary that comes with prostate cancer. To help, we compiled a list of the most common terms used in discussions about prostate cancer.

### The Basics

**Lobe:** The sections of the prostate. There are three sections of the prostate, one central lobe and one lobe on either side of the central lobe.

**Lymph Node:** A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid) and store lymphocytes (white blood cells). They are located along lymphatic vessels. Also called lymph gland.

**Primary Cancer:** The place in the body where the cancer started. If a primary prostate cancer spreads to other parts of the body, it has metastasized. For example, a brain tumor from prostate cancer is still prostate cancer and not brain cancer. It is a metastasis of prostate cancer.

**Metastasis:** The spread of cancer from one part of the body to another. This happens through the lymph system or through the blood stream. A tumor formed by cells that have spread is called a “metastatic tumor” or a “metastasis.” The metastatic tumor contains cells that are like those in the original (primary) tumor. The plural form of metastasis is metastases (meh-TAS-tuh-SEEZ).

**Prostate-specific Antigen (PSA):** Prostate-specific Antigen (PSA) is a substance in the blood that’s made by the prostate gland. It can be used to detect unusual activity in the prostate.

**Biochemical recurrence:** Biochemical recurrence is a rise of prostate-specific antigen (PSA) levels in the blood of a prostate cancer patient after treatment with surgery or radiation. Biochemical recurrence may occur in patients who do not have symptoms. It may mean that the cancer has come back.

### Diagnostic Tests

**PSA blood test:** The PSA is a blood test that is done to see what your PSA level is and how it changes over time. Changes in PSA can be used to detect early stages of prostate cancer.

**Transrectal ultrasound (TRUS):** For this test, a small wand is put into your rectum. It gives off sound waves and picks up the echoes as they bounce off the prostate gland. The echoes are made into a picture on a computer screen.

**Prostate biopsy:** For a biopsy (by-op-see), the doctor takes out a small piece of tissue where the cancer seems to be. This tissue is checked for cancer cells. A core needle biopsy is often used to find prostate cancer.

**Lymph (limf) node biopsy:** Lymph nodes are small bean-shaped parts of the immune system. A lymph node biopsy may be done if the doctor thinks the cancer might have spread from the prostate to nearby lymph nodes.

**Computerized (Axial) Tomography (CT/CAT) scan:** CT/ CAT scans detect smaller tumors than the x-ray detects and help the doctor determine if the tumor has spread to lymph nodes or areas surrounding the prostate.

**Magnetic Resonance Imaging (MRI):** MRIs use magnetic fields to create clear images of body parts, including tissues, muscles, nerves and bones. MRIs make better images of organs and soft tissue than other scanning techniques, such as computed tomography (CT) or x-ray. MRI is especially useful for imaging the brain, the spine, the soft tissue of joints and the inside of bones.

## Treatment

**Adjuvant:** Treatment given after the primary treatment to increase the chances of a cure. Usually involves chemotherapy or radiation.

**Neoadjuvant:** Treatment given before the primary treatment. Usually involves chemotherapy or radiation.

**Active Surveillance:** Active Surveillance is only done in men who would otherwise be eligible for treatment, and is “active” by definition and requires routine follow-up, exams, labs and biopsies.

**Watchful Waiting:** Watchful Waiting is literally waiting for symptoms to show up in men who have other competing comorbidity or advanced age precluding them from initial treatment.

## Surgery

**Radical Prostatectomy:** A radical prostatectomy is an operation to remove the prostate gland and some of the tissue around it.

## Chemotherapy and Targeted Chemo

An important advancement in prostate cancer treatment has been the discovery of targeted therapies. Because traditional chemotherapies go throughout the entire body to target fast growing cells, healthy cells and tissues are affected along with the cancerous cells. Targeted treatments attack cancer in more specific ways, usually by interrupting the ways that cancer cells grow or divide, such as:



**Chemotherapy:** Drugs used to kill rapidly dividing cells in the body, which include cancer cells, but also some healthy cells. It is a systemic treatment, which means it circulates through the body and kills cancer cells throughout.

## Radiation

**General Radiation (External Beam):** Use of carefully aimed doses of radiation at specific sections of the lungs or surrounding areas, such as the neck or center of the chest.

**Stereotactic Radiosurgery (SRS), Stereotactic Radiotherapy (STR), Stereotactic Body Radio-therapy (SBRT):** A precise delivery of a single, high dose of radiation in a one-day session done to the body (CyberKnife).

**Brachytherapy:** A type of radiation therapy in which radioactive material sealed in seeds is placed directly into or near a tumor. Also called uranium seed implants, radiation brachytherapy, internal radiation therapy, and implant radiation therapy.

## Ablation Therapies

**Radiofrequency Ablation (RFA):** Uses radio waves to heat up and destroy tumors.

**Cryoablation:** Uses liquid nitrogen or argon gas to freeze tumors, also known as cryotherapy.

## Immunotherapies

**Immunotherapy:** uses the power of the body's own immune system to treat cancer. Can be used for many types of cancer, either alone or in combination with other treatments.

## Symptoms/Side Effects

**Cachexia:** Loss of body weight and muscle mass and weakness that may occur in patients with cancer.

**Neuropathy:** A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and may worsen over time. It is a common side effect from platinum-based chemotherapy drugs.

**Incontinence:** Lack of voluntary control over urination or defecation, usually a side effect of radiation.

**Impotence:** Inability to have an erection, a possible side effect of prostate cancer treatment.

## Health Care - Words that Matter

To reduce this confusion and help patients better understand the jargon they will likely encounter in health care, the below glossary is a resource to help patients understand these words with plain language definitions. This “Words that Matter” glossary are part of a branded project supported by Patient Advocate Foundation and the Patient Action Council and is reprinted with their permission.

### ***Affordable Care Act (ACA, ObamaCare)***

A comprehensive healthcare reform law enacted in 2010 and that included many provisions that impact today’s current healthcare plans.

### ***Allowed Amount (Negotiated Rate)***

The contracted payment amount agreed between a provider in your network and the insurer as compensation for a particular service. If you owe any co-insurance or cost-sharing, this is the amount used to define your costs.

### ***Benefits (Covered Benefits)***

The entire package of defined medical procedures, therapies, prescriptions and services listed within your insurance plan documents in which the insurer agrees to provide compensation on your behalf.

### ***Brand-Name Drugs***

A brand-name drug is a medicine that has been discovered, developed, and marketed by a pharmaceutical company. Once a new drug has been discovered, a patent is filed on it that prevents a rival company from creating a generic version for up to 20 years. Brand-name drugs tend to be more expensive than their generic counterparts.

### ***Co-insurance***

The percentage amount you pay towards a covered healthcare service. The amount is calculated based on the allowed amount for that service, and is only relevant after you have paid your full deductible amount.

### ***Commercial Health Insurance (Private Insurance)***

Health insurance offered by private for-profit companies in exchange for a premium paid by enrollees. Commercial insurance plans can be structured in many different ways and are frequently offered with numerous plan types. Also known as private health insurance.

### ***Co-payment (Co-pay)***

The fixed amount you are responsible to pay for a covered health service, usually due at the time you receive the care. If your plan is subject to co-pays, the amounts are defined within your plan language.

**Coverage**

An agreement between you and your insurer where they cover some of your health care costs in exchange for a premium. If you have coverage in place, you have agreed to the terms of the agreement.

**Coverage Details**

The provisions and conditions applicable to the agreement between you and your insurer to pay for your health care costs.

**Covered Services**

The medical services, procedures or treatments that are listed within your coverage details that the insurer has agreed to provide payment on your behalf.

**Deductible**

The amount you pay for covered health care services before your insurer begins to pay. Typically, you must reach your full deductible amount before your insurance will cover any of the costs associated with covered services. (excluding preventive services)

**Drug Formulary (Preferred Drug List)**

A drug formulary is a list of medications covered by your health insurance plan separated into several tiers or categories based on the price of the drug. Also commonly referred to as Drug List or Preferred Drug List.

**Effective Date**

The first date you become covered for health insurance under your plan.

**Emergency Room (ER)**

The site where you can be treated for acute illness, trauma or life-threatening situations, in which emergency-certified providers are prepared to provide prompt treatment. Frequently co-located with a hospital, but may also be a stand-alone facility.

**Employer-Based Health Plan**

Health insurance sponsored and coordinated by your employer and available to you as an employee. Many employer-based health plan premiums are covered in part by the employer, lowering the amount you owe in premiums. Also referred to as job-based health plans.

**Enrollment Date**

The date when you signed up for health insurance and officially submitted your application and enrollment paperwork.

**Excluded Services (Uncovered Services)**

Health care your insurer has stated that it does not pay for, as defined in your plan language.

**Generic Drugs**

Generic drugs are required to be identical to brand-name drugs in active ingredient, dosage, safety, strengths, quality, performance, and intended use. They can be manufactured by several different drug companies once the original patent has expired. They are usually sold at significant discounts from the branded-drug price.

**Health Insurance Card**

A wallet-sized card issued by your insurer when enrollment is complete and coverage begins. The card serves as proof of insurance and contains basic information regarding the insured member, the plan structure, co-payments and co-insurance, and has contact information to reach the insurer.

**Health Maintenance Organization (HMO)**

A plan where you pay a higher premium in exchange for defined co-payments and co-insurance amounts associated with care due at the time of service. Most HMO's do not have a deductible, and are structured to reduce the exposure to large out-of-pocket costs. HMOs may also require your care to be provided by members of its network in order to be covered, with limited or no benefits for care received by a provider outside of this network.

**High Deductible Health Plans (HDHP)**

A plan that typically has lower premiums but higher deductibles that must be met before the insurer begins to pay toward your care.

**In-Network (Preferred)**

The set of doctors, hospitals, laboratory, pharmacy and other providers that have agreed to provide healthcare services to your plan's members at set rates is called the insurer's network. In-network is a description that refers to a provider who is a member of this network. Preferred provider is another term used for in-network provider.

**Insurance (Health Insurance)**

A type of contract in which you agree to pay a premium to a company in exchange for help paying for the cost of medical services should you require them during the time period of coverage. You must pay the premium even if you do not receive any care during that period.

**Marketplace (Health Insurance Marketplace)**

A shopping resource where people can compare, research and purchase insurance plans for the next plan year. Marketplaces are available in each state and are the only places where you can qualify and receive premium tax credits to help offset the cost of your monthly premium for the plan you select.

**Navigator**

An individual or organization that is trained to help you when shopping for insurance, and can assist in completing enrollment forms or evaluating plan options. Navigators are required to be unbiased and work to help you find the best health plan for your needs, all at no cost to you.

**Network**

Medical providers that have contracted with your plan to provide your care at a reduced negotiated rate. This group of providers is referred to as your network or your insurer's network.

**Non-Covered Services (Excluded Services, or Un-Covered Services)**

Health care services your insurer does not pay for as part of your plan agreement.

**Non-preferred Brand-Name Drugs**

A non-preferred drug is a medication that has been determined to have a clinically equivalent drug, already on the list of preferred prescriptions. Non-preferred brand-name drugs have a higher cost to you than preferred brand name drugs, and may be new to the market. Sometimes plans have limited or no coverage of non-preferred brand name drugs.

**Open Enrollment**

A defined period of time each year during where an individual may select or change his or her health insurance plan for the following plan year. Open enrollment periods and time of year vary based on the whether seeking Commercial insurance, employer-based insurance or Medicare insurance. Medicaid does not have an open enrollment period.

**Out-of-Network**

The description given to doctors, hospitals, laboratory, pharmacy and other providers that do not have a current agreement in place with your insurer to provide you discounted rates. Out-of-network providers may charge you any amount they want in exchange for their services, and are typically higher than the negotiated rate of in-network providers. Non-Preferred provider is another term used for an out-of-network provider. Your plan may have stated that it will not cover any portion of care provided by a out-of-network doctor; check your plan documents to be certain.

**Out-of-Pocket Maximum**

The most you'll have to pay for covered services in a policy period before your insurer will pay 100% of the cost toward covered services. Typically includes your deductible and additional patient responsibility elements like copayments and coinsurance. Premiums and un-covered services do not count towards your out-of-pocket maximum.

**Preferred Brand-Name Drugs**

These are drugs for which generic equivalents are not available and have proven clinical and cost effectiveness. They cost more than generics, but less than non-preferred brand-name drugs.

**Preferred Drug List (Drug List)**

A Preferred Drug List is another name for a drug formulary. The two are interchangeable or sometimes just known as a Drug List.

**Preferred Provider Organization (PPO)**

A type of health plan provided to you in exchange for your premium, that allows you access to a network of medical providers, such as hospitals and doctors who agree to provide you care at a discounted rate. This plan type may allow care outside of these providers, but typically will do so at a higher cost to you.

**Premium**

When you decide to enroll in a health plan, this is the amount you agree to pay in exchange for having an insurer issue you insurance coverage. This amount is typically due on a monthly basis, but can be charged in other frequency. You must pay the premium amount regardless if you receive any care by medical providers during your plan term. If you do not pay your premium, you are canceling the contract and the insurer does not have to pay towards your care.

**Premium Tax Credit (Tax Subsidy)**

A tax credit that can help you afford health coverage through the Health Insurance Marketplace by providing instant savings on premium payments. In order to receive the Premium Tax Credit you must meet and maintain eligibility criteria throughout your plan year.

**Preventive Services**

Routine care that includes screenings, check-ups, and patient counseling to prevent illnesses, disease, or other health problems. The Affordable Care Act mandates that preventive care is included in coverage with no out-of-pocket charges connected to these services. (Grandfathered plans may be excluded from the Affordable Care Act provisions)

**Primary Care Physician (PCP)**

A doctor skilled in family medicine and general internal medicine that serves as a central point of coordination for your care. This doctor is equipped to treat many common care needs and can refer you to a specialist or another doctor when needed. If you have a HMO plan type, the primary care physician is your main doctor on record with the insurance company.

**Prior Authorization (PA)**

A restriction placed on certain drugs that require your doctor get authorization from your benefit plan before your plan will cover the medication. Sometimes this is referred to as pre-approval.

**Provider**

Any medical professional who provides health services to patients. Frequently thought of as a doctor or physician, but also includes pharmacists, laboratory professionals, physical therapists, nurses, radiologists, clinical social workers, or medical facilities.

**Quantity Limits (QL)**

A coverage limit to how many doses you can get of a particular drug, determined by your plan.

**Special Enrollment Period**

A time when you can enroll in insurance outside of open enrollment due to a special circumstance.

**Summary of Benefits & Coverage (SBC)**

short, plain-language overview of your insurance plan, including an outline of your coverage benefits, out-of-pocket expenses and exclusions. The Affordable Care Act standardized this document to ensure that within all commercial and employer-based health plans, you can easily compare and contrast various plans. This is not a substitute for the full-length document which defines your complete coverage benefits, provided to you by your insurer.

**Step Therapy (ST)**

A restriction placed on certain drugs that require you first try an alternative medication that is cheaper and also has been determined to be safe and effective.

**Tax Penalty (Fee)**

A charge that must be paid if you don't have insurance or your insurance doesn't meet the minimum essential coverage in a given calendar year. The penalty amount varies based on how long you are without coverage and your annual income. The penalty is due at the same time you file your income taxes for the previous tax year.

**Tiers**

Tiers are the categories or levels that covered drugs are sorted into, usually presented in order from lower cost to higher cost. Plans frequently have between 3 and 7 tier levels that medications are grouped in as part of the formulary.

**Urgent Care Facility**

A site where you can be treated for non-life threatening illness without an appointment and be seen by medical providers who are prepared to provide prompt treatment for common conditions. Urgent care facilities typically are open longer than a provider's office each day and see patients on weekends. Urgent care facilities are frequently stand-alone facility not connected to a hospital or doctor's office.

## ZERO Patient Programs

You are not alone in your prostate cancer journey. ZERO offers the following patient support programs to help you along the way. These programs are offered at no cost to you.



### **ZERO360: Comprehensive Patient Support**

[zerocancer.org/zero360](http://zerocancer.org/zero360)

Our team of experienced case managers is ready to help you and your family through your personal prostate cancer journey.

1-844-244-1309 (Toll-Free)

Monday - Thursday 8:30 a.m. - 5:00 p.m. ET

Friday 8:30 a.m. - 4:00 p.m. ET

Closed on all major holidays

### **Decode Your Prostate Cancer**

[zerocancer.org/decode](http://zerocancer.org/decode)

Eligible patients with metastatic prostate cancer can access their molecular profiles for free and receive a tailored plan of care based on the mutations driving their cancers. This program is provided in partnership with Perthera, a leading company in precision medicine.

### **MENtor: Peer Support**

[zerocancer.org/mentor](http://zerocancer.org/mentor)

MENtor is a support network for newly diagnosed men living with prostate cancer, as well as men who have experienced a recurrence. Our trained, volunteer MENtors represent many different prostate cancer journeys and have a wealth of insights to share based on their experiences.

### **Free Testing Database**

[zerocancer.org/testing](http://zerocancer.org/testing)

To help men across the country find testing near them, we have compiled a national database of prostate cancer screening sites. These sites have indicated that they provide some free or low-cost prostate cancer testing during the year.



## NOTES

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