

International Prostate Cancer Foundation

# ADVANCED PROSTATE CANCER Patient Guide

A comprehensive resource on advanced prostate cancer for patients and families.

fightingprostatecancer.org

## INTRODUCTION

### **About this guide**

There are no two ways about it: getting diagnosed with cancer is hard and life-changing. Despite increasing optimizer about treatment, today's cancer landscape can be challenging as patients have access to an unprecedented amount of information.

There are literally millions of cancer-related webpages, blogs, and videos available at your fingertips. A cancer diagnosis can be disorienting, and for many, the overwhelming volume of information available can be more of a burden than an aid.

This guide focuses all the information available about advanced prostate cancer into one consolidated resource. It is for any person(s) who has an advanced prostate cancer diagnosis, who is in treatment, or is concerned about a rising PSA. Beyond that, it's for any loved one or caregiver who wants to cut through the information noise and get directly to need-to-know information for prostate cancer patient navigation.

The Advanced Prostate Cancer Guide is not intended to be followed like a book you read from beginning to end. Rather, it can be referenced, as needed, for each topic that is relevant to your cancer experience.

### Who should read this guide?

All men, whether they have or have not been diagnosed with prostate cancer, would benefit from reading this guide. Caregivers, family, and friends may also find this book helpful. It may help you discuss and decide with doctors what avenue of care is best.

To learn more about prostate cancer and for the most update information please visit fightingprostatecancer.org. It may also be helpful to download the Prostate Cancer Guide Vol. 1 and the Prostate Cancer Caregiver Guide Vol. 2 from the resources center of the website. It provides more in-depth information on prostate cancer, research, caregiving and prostate cancer treatment.

### Making sense of medical terms

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn. Reference the glossary in the back of Vol 1. for definitions of terms.

Don't be discouraged as you read. Keep reading and review the information. Don't be shy to ask your treatment team to explain a word or phrase that you do not understand.

### **About IPCF**

Founded in 2008, The International Prostate Cancer Foundation is a not-for-profit charitable organization with a voluntary faculty of international expert physicians, survivors and advocates who have joined in the fight against prostate cancer. Founded to fill a void in men's health advocacy and to raise awareness and support scientific advances in prostate cancer. Our mission is to cure those afflicted with the disease and to help prevent it in those who are predisposed to it.

Conceived by cancer survivors, our mission is clear, and our approach is unique. Our foundation is led by Dr. Vipul Patel, a practicing urologist with a worldwide patient base. This, combined with our expert volunteer board, gives us a unique perspective of the disease on both a clinical and non-clinical level.

The spirit of our foundation is formed from the inspiration of our doctors, patients, and healthcare advocates. Our mission is to serve, educate, and innovate to help men understand the risks and what to do if they are diagnosed with prostate cancer.

Subjects depicted are models and are used for illustrative purposes only. Prostate cancer standards of practice change regularly. For the most up-to-date information, please visit fightingprostatecancer.org or consult a healthcare professional.

This guide was produced in 2022-2023 by the International Prostate Cancer Foundation (IPCF). Founded in 2008, The International Prostate Cancer Foundation is a not-for-profit charitable.

This guide is provided to the general public to disseminate health-related information. The included information is not intended to be used for diagnosing or prescribing. Please consult your physician before undertaking any form of medical treatment and/or adopting any exercise program or dietary guidelines. The information resources listed are not the property of the International Prostate Cancer Foundation. The International Prostate Cancer Foundation does not assure the accuracy or timeliness of the information and provides these references for your convenience only.

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- from your doctor

### **AFRICAN AMERICAN MEN ARE TWICE** as likely to die from prostate cancer

With early diagnosis and treatment, survival rates are over 90%

### Having a father/brother diagnosed more than doubles a man's risk



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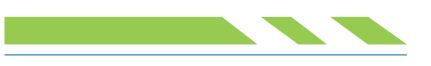
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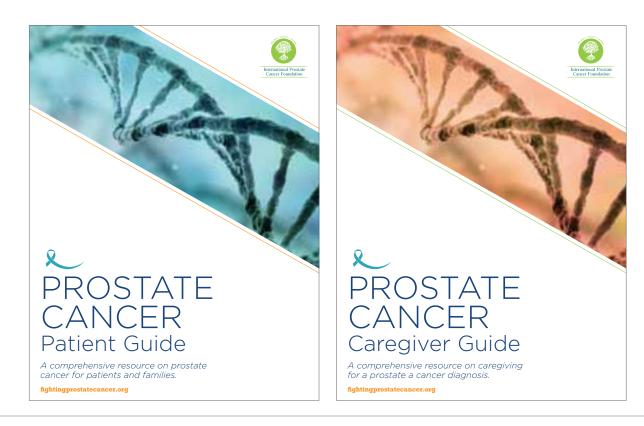
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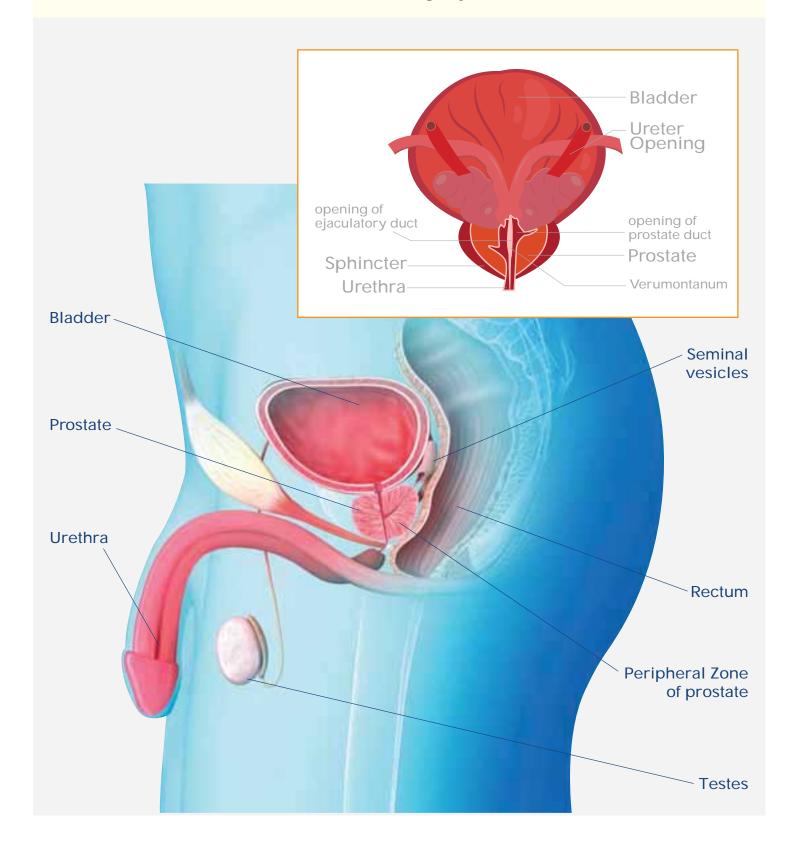


### For more information on Prostate Cancer and Caregiving for a prostate cancer patient please visit the downloads section of the resources center to find volume 1 and 2 patient guides as downloadable pdfs.

### www.fightingprostatecancer.org/resources-1

## ANATOMY OF THE PROSTATE

The prostate gland looks like a chestnut, is located just below the urinary bladder and is run through by the urethra.



## 1. ABOUT YOU AND PROSTATE CANCER

### **General Information**

According to the *National Cancer Institute*, prostate cancer is the second most common type of cancer among men in the United States. Men with certain risk factors are more likely than others to develop the disease.

Published data suggests that one of the most important factors in treating prostate cancer is *early diagnosis and accurate treatment* by experienced doctors. Before a treatment plan is determined, however, it is important to understand the disease and to research all the options available.

Cancer is a condition in which a normal cell becomes abnormal and starts to grow uncontrollably without having the signals or "brakes" that stop typical cell growth.

Prostate cancer starts in the prostate gland, a small gland located below the bladder, that is responsible for secreting one of the components of semen. Prostate cancer develops when abnormal cells in the prostate gland start to grow more rapidly than normal cells, and in an uncontrolled way. Most prostate cancers grow more slowly than other types of cancer, and even the more aggressive prostate cancers tend to grow more slowly than other types of cancer. Compared with other cancers, prostate cancer has one of the highest five-year survival rates.

In many cases, prostate cancer is relatively slow growing, which means that it takes several years to become large enough to be detectable, and even longer to spread outside the prostate, or metastasize. However, in some cases the growth is more aggressive and may need more urgent treatment.

Many men live with prostate cancer for many years without symptoms and without it spreading. Early (or localized) prostate cancer means cancer cells have grown but, as far as it is possible to tell, have not spread beyond the prostate.

### The Anatomy of the Prostate

The prostate begins to form while a baby is inside his mother's womb. After birth, the prostate keeps growing and reaches nearly full-size during puberty. At this point, it is about the size of a walnut. Testosterone causes the prostate to grow slowly in most men. However, the prostate may grow to a large size in some men and cause problems in passing urine.

The prostate sits under the bladder and in front of the rectum. The prostate is only present in men and is important for reproduction, because it supplies the fluids needed for sperm to travel and survive (sperm is not made in the prostate; it is made in the testes). This white-colored fluid mixes with the sperm and other fluids to form semen. Semen is ejected from the body through the penis during ejaculation. The fluid from the prostate specifically protects sperm from the acid inside a woman's vagina.

The prostate is divided into several anatomic regions, or zones. Most prostate cancer starts in the peripheral zone (the back of the prostate) near the rectum. That's why examining the prostate via a gloved finger in the rectum, known as digital rectal exam (DRE), is a useful screening test (*see page 28 for illustration of DRE*).

The seminal vesicles are rabbit-eared structures that store and secrete a large portion of the ejaculate. These structures sit on top of the prostate. The neurovascular bundle is a collection of nerves and vessels that run along each side of the prostate, helping to control erectile function. They are usually a short distance away from the prostate, but sometimes they attach to the prostate itself.

The bladder is like a balloon that gets larger as it fills up, holding urine until the body is ready to void. The urethra, a narrow tube that connects to the bladder, runs through the middle of the prostate and along the length of the penis, carrying both urine and semen out of the body; it is the hose that drains the bladder.

The rectum is the lower end of your intestines that connects to the anus, and it sits right behind the prostate.

As shown in the illustration, the prostate is located below the bladder near the base of the penis. Urine from the bladder travels through the urethra, which passes through the prostate and into the penis. Above the prostate and behind the bladder are two seminal vesicles. Seminal vesicles are also glands that make a fluid that is part of semen.

Inside the prostate, 30 to 50 small sacs make and hold the white-colored fluid. The fluid travels in ducts to the urethra during ejaculation. Around the sacs and ducts is connective tissue.

### The Biology Of Prostate Cancer

To properly understand diagnosis and treatment options, it's important to understand how prostate cancer grows. A normal prostate uses androgens (including testosterone and dihydrotestosterone, or DHT) during its development and everyday function. Once prostate cancer forms it feeds on androgens and uses them as fuel for growth. This is why one of the backbones of treatment for men, especially with advanced prostate cancer, is to lower a man's androgen levels with drugs collectively termed "hormone therapy."

Prostate cancer occurs when a normal prostate cell begins to grow out of control. In many cases, prostate cancer is a slowgrowing cancer that does not progress outside of the prostate gland before the time of diagnosis.

Prostate cancers that are composed of very abnormal cells are much more likely to both divide and spread faster from the prostate to other regions of the body. Often, prostate cancer spreads first to tissues that are near the prostate, including the seminal vesicles and nearby lymph nodes.

Researchers have identified various biological and genetic subtypes of prostate cancer. It is possible for any given prostate cancer tumor to contain multiple subtypes of prostate cancer. Doctors and researchers are only just now beginning to use subtyping to guide treatment recommendations, thanks in part to active and ongoing research *(see Understanding Your Diagnosis for more detailed information on page 27)*.

### What Is Prostate Cancer?

Prostate cancer is a type of urologic cancer — a group of cancers that affect the urinary system. Prostate cancer starts within cells of the prostate gland, which is only found in men. The prostate gland surrounds the urethra and produces seminal fluid. Normally, these cells grow and divide to create new healthy cells as the body needs them. These healthy cells replace the old or damaged cells that die. It is a balanced process when it works right.

When the balance is off, a damaged or old cell does not die and isn't removed by the body's immune system. This cell then creates new, faulty cells that keep dividing uncontrollably, which may cause tissue growths called tumors.

Cancerous tumors are dangerous because the cancer cells can spread into nearby tissues, or metastasize. They can grow or break off and travel into other places in the body through the blood or lymph system, forming new tumors.

### What Causes Prostate Cancer?

Medical professionals and researchers aren't completely sure what causes prostate cancer. It's likely that several different factors come into play, but researchers are still investigating which factors have the greatest impact and how they cause the cancer to develop. At a very basic level, researchers know that prostate cancer develops as a result of DNA mutations in one or more prostate cells. These DNA mutations may be inherited.

For instance, some people are born with tumor suppressor genes (RNASEL, BRCA1 and BRCA2) that don't function the way they should. This can allow cancerous cells to develop, grow and eventually form a tumor.

Caused by increased hormone levels. For instance, too many androgens (male hormones, such as testosterone) may program prostate cells to grow at an abnormally high level, and DNA mutations may occur as a result.

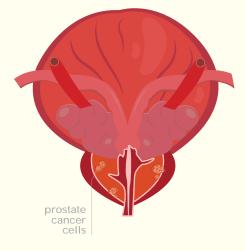
Acquired over time. Although the correlation isn't fully understood, being obese or over the age of 50 are risk factors for prostate cancer. These aren't proven causes of prostate cancer, but rather can make a person's DNA more likely to mutate over time.

### Is There A Cure For Prostate Cancer?

When people think about cancer treatment success, they often think of the word "cure." Sometimes statisticians think of "cure" as a function of time: is 5 years without a cancer recurrence equal to a cure? Or is it 10 years? Unfortunately, in some men, prostate cancers can recur even 10 years after treatment. So instead of using the term "cure," doctors commonly use terms such as biochemical control (PSA levels kept at bay with

### WHAT IS PROSTATE CANCER?

Prostate cancer develops when abnormal cells in the prostate gland start to grow more rapidly than normal cells in an uncontrolled way.



### WHAT ARE THE SYMPTOMS OF PROSTATE CANCER?



weak or interrupted flow of urine



painful ejaculation

blood in the urine or semen

frequent urination (especially at night)

painful urination

persistent pain in the back, hips or pelvis

## PROSTATE CANCER RISK **MYTHS**

The below have been disproven as prostate cancer risks.



**Sexual Activity** 



medication) or freedom from developing metastatic disease (the cancer has not spread to distant organs) to help quantify the success of prostate cancer treatment.

### **Risk Factors**

A risk factor is anything that affects your chance of getting a disease. Different cancers have different risk factors. Some risk factors, like smoking or diet, can be changed. Others, like a person's age or family history, can't be changed.

Having one or several risk factors does not mean that you will get the disease. Many people with one or more risk factors never get cancer, while others who get cancer may have had few or no known risk factors.

Age: Age is the main risk factor for prostate cancer, and the disease is rare in men younger than 45; only 1 in 10,000 men under age 40 will be diagnosed. However, with advanced screening, men as young as 30 have been diagnosed and treated for prostate cancer. The chance of getting prostate cancer increases sharply as a man gets older. In the United States, more than 65% of all prostate cancers are diagnosed in men over the age of 65.

Family History: A man's risk is higher if his father or brother had prostate cancer. This risk is further increased if the cancer was diagnosed in family members at a younger age (less than 55 years of age) or if it affected three or more family members.

Geography: Prostate cancer is most common in North America, northwestern Europe, Australia, and the Caribbean islands. It is less common in Asia, Africa, Central America, and South America.

The reasons for this are not clear. More intensive screening in some developed countries probably accounts for at least part of this difference, but other factors such as lifestyle differences, such as diet, are likely to be important as well.

Race: It is more common in African-American men than in Caucasian men. It is less common in Asian and Native-American men.

Certain Prostate Changes: Men with cells called High-Grade Prostatic Intraepithelial Neoplasia (PIN) may be at increased risk. These prostate cells look abnormal under a microscope.

**Inflammation of the Prostate:** Some studies have suggested that prostatitis (the inflammation of the prostate gland) may be linked to an increased risk of prostate cancer, but other studies have found no such link. Inflammation is often seen in samples of prostate tissue that also contain cancer. The link between the two is not yet clear and is an active area of research.

**Certain Gene Changes:** Several inherited gene changes seem to raise prostate cancer risk, but they probably account for only a small percentage of cases overall.

For example: Inherited mutations of the BRCA1 or BRCA2 genes raise the risk of breast and ovarian cancers in some families. Mutations in these genes (especially in BRCA2) may also increase prostate cancer risk in some men.

Men with Lynch Syndrome (also known as Hereditary Non-Polyposis Colorectal Cancer, or HNPCC), which is a condition caused by inherited gene changes, have an increased risk for several cancers, including prostate cancer.

**Diet:** The exact role of diet in prostate cancer is not clear, but several factors have been studied. Some studies suggest that men who eat a diet high in animal fat or meat may be at increased risk. In other studies, men who ate the most dairy products — such as milk, cheese and yogurt — had the highest risk of prostate cancer.

Overall, study results have been mixed, and the risk associated with dairy products is thought to be small. The fact remains that men who eat a diet rich in fruits and vegetables may have a lower risk.

Lack of Exercise and a Sedentary Lifestyle: Exercise can help you maintain or lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce your risk of heart disease and other cancers. If you are overweight or obese, work on losing weight.

### **Risk Myths**

Sexual Activity: High levels of sexual activity or frequent ejaculation have been rumored to increase prostate cancer risk. This is untrue. In fact, studies show that men who reported more frequent ejaculations had a lower risk of developing prostate cancer.

**Vasectomy:** A vasectomy was originally thought to increase a man's risk, but this has since been disproven.

**Medications:** Several recent studies have shown a link between aspirin intake and a reduced risk of prostate cancer by 10-15%. This may result from different screening practices, through a reduction of inflammation, or other unknown factors.

**Alcohol:** There is no link between alcohol and prostate cancer risk.

**Vitamin E:** Recent studies have NOT shown a benefit to the consumption of vitamin E in the prevention of prostate cancer.

### Prevention

There are many things that men can do to reduce or delay their risk of developing prostate cancer.

Why is prostate cancer so common in Western culture and much less so in Asia? It is believed the major risk factor is diet - foods that produce oxidative damage to DNA.

What can I do to prevent or delay the onset of the disease? There's no sure way to prevent prostate cancer. Study results often conflict with each other and most studies aren't designed to definitively prove if something prevents prostate cancer. As a result, no clear ways to prevent prostate cancer have emerged.



In general, doctors recommend that men with an average risk of prostate cancer make choices that benefit their overall health. Below are some things that have shown some evidence of lowering your prostate cancer risk.

**Exercise:** Exercise can help you maintain your weight, or it can help you lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce your risk of heart disease and other cancers. If you are overweight or obese, work on losing weight. You can do this by reducing the number of calories you eat each day and increasing the amount of exercise you do. If you have a healthy weight, work to maintain it by exercising most days of the week and choosing a healthy diet that's rich in fruits, vegetables and whole grains.

If you don't already exercise, make an appointment with your doctor to make sure it's OK for you to get started. When you begin exercising, go slowly. Aim for 30 minutes of exercise most days of the week.

**Reduce Fat:** Try to keep the amount of fat you eat from red meat and dairy products to a minimum. In some studies, men who ate the highest amount of fat each day had an increased risk of prostate cancer. While this association doesn't prove that excess fat causes prostate cancer, reducing the amount of fat you eat each day has other proven benefits, such as helping you control your weight and helping your heart stay healthy.

To reduce the amount of fat you eat each day, limit fatty foods or choose low-fat varieties. For instance, reduce the amount of fat you add to foods when cooking, select leaner cuts of meat, and choose low-fat or reduced-fat dairy products. In studies, men who ate the most dairy products — such as milk, cheese and yogurt — each day had the highest risk of prostate cancer. But study results have been mixed, and the risk associated with dairy products is thought to be small.

**Make Smarter Food Choices:** Eat more fish. Evidence from several studies suggest that fish can help protect against prostate cancer because fish have "good fat" such as omega-3 fatty acids. Avoid trans fatty acids (found in products such as margarine). Try to incorporate tomatoes that are cooked with olive oil, which has also been shown to be beneficial, along with cruciferous vegetables (like broccoli and cauliflower) into many of your weekly meals.

Eat more fat from plants than from animals. In studies that looked at fat consumption and prostate cancer risk, fats from animals were most likely to be associated with an increased risk of prostate cancer. Animal products that contain fats include meat, lard and butter.

You might consider using plant-based fats instead of animal fats. For instance, cook with olive oil rather than butter. Sprinkle nuts or seeds on your salad rather than cheese.

Soy and green tea are also potential dietary components that may be helpful, as well as broccoli, pomegranate juice, tomatoes and legumes.





What about supplements? Avoid over-supplementation with megavitamins. Too many vitamins, especially folate, may "fuel the cancer", and while a multivitamin is not likely to be harmful, if you follow a healthy diet with lots of fruits, vegetables, whole grains, fish, and healthy oils, you likely do not even need a multivitamin. Watch your calcium intake. Do not take supplemental doses far above the recommended daily allowance. Taking calcium supplements is fine but avoid taking more than 1,500 mg of calcium a day. Always check with your healthcare team before taking anything on your own.

Seek medical treatment for stress, high blood pressure, high cholesterol, and depression. Treating these conditions may save your life and will improve your survivorship with prostate cancer. A yearly rectal examination and PSA test will also go a long way in early detection or diagnosis.

Relax and enjoy life: Reducing stress in the workplace and home will improve your survivorship and lead to a longer, happier life.

### Symptoms Of The Disease

Typically, there are no symptoms in the early stages of prostate cancer and even with advanced prostate cancer there may be no symptoms. Where symptoms do occur, they are often due to non-cancerous conditions, such as benign prostate hyperplasia (BPH).

Men over the age of 50 often experience urinary problems. An otherwise normal prostate may grow, which can change patterns of urine flow. This enlargement is called benign prostate hyperplasia (BPH) and is generally a normal part of aging - it is not cancer.



You should consult with your doctor if you experience any of the symptoms below as these symptoms can also indicate the presence of other diseases or disorders.

### CALL YOUR DOCTOR IF YOU EXPERIENCE . . .



Symptoms of advanced prostate cancer may include unexplained weight loss, feeling the frequent or sudden need to urinate, or pain in the lower back/pelvic area or sciatica. These are not always a sign of prostate cancer, but you should speak with a doctor if you have any of these symptoms or other urinary problems.

### **Psa Progression**

We typically refer to Advanced Disease as the state of prostate cancer that has grown beyond the prostate and is unlikely to be cured with surgery or radiation alone. After a man experiences PSA progression after surgery or radiation, hormonal therapy is often given at some point, and often for many years. Some men will not require any hormonal therapy, however, many men's cancer will continue to progress despite the above hormonal treatments and will require more aggressive therapy. This comes in the form of additional second- and third-line hormonal therapies, investigational agents (many are in trials right now from new hormonal therapies to prostate cancer vaccines to bone-targeting drugs), and chemotherapy.

### For more information on prostate cancer please download the Prostate Cancer Patient Guide Volume I.

Visit the downloads section of the resources center to find volume 1 (prostate cancer) and 2 (caregiving for prostate cancer) patient guides as downloadable pdfs.

www.fightingprostatecancer.org/resources-1

## 2. LOCALLY ADVANCED PROSTATE CANCER

The term advanced prostate cancer means the disease has spread from the prostate to other parts of the body. It develops when prostate cancer cells move through the blood stream or lymphatic system.

When prostate cancer spreads beyond the prostate, or returns after treatment, it is often called metastatic prostate cancer. (*see cancer staging on page 36*) Some men with newly diagnosed prostate cancer start out with an advanced progression of the disease. In others, advanced prostate cancer develops after the original treatment for the localized tumor.

Cancer that spreads outside the prostate gland to the lymph nodes, bones, or other areas is called metastatic prostate cancer. Currently, no treatments can cure advanced prostate cancer. However, there are ways to help control its spread and related symptoms.

Advanced prostate cancer is usually treated with a combination of different approaches, which may include hormone therapy, chemotherapy, immunotherapy, or radiation. Some males may be offered surgery to remove the prostate if their cancer's spread appears to be limited to just the prostate gland or the lymph nodes and there is no evidence of spread to other parts of the body. In other cases, such as when the cancer has spread to the bones or other tissues in the body (called "distant metastasis"), surgery is not typically offered.

Hormone (endocrine) therapy, known as androgen ablation or androgen suppression therapy, is the main treatment for advanced prostate cancer. However, your choice of treatment is influenced by several factors, including your current medical condition, treatments you've already received, location and extent of your cancer, and presence or absence of symptoms. For patients with PSA-only cancer, the prostate-specific antigen (PSA) doubling time is also considered. *For more in-depth guidance on treatments, please reference: Section 4. Treatment Options.* 

Treatments that slow the spread of advanced prostate cancer and relieve symptoms often cause side effects. Some patients, often those who are older, decide that the risk of side effects outweighs the benefits of treatment. These patients may choose not to treat their advanced prostate cancer.

It's important to remember that researchers are always searching for new and better treatments that will cause fewer side effects, better disease control, and longer survival rates.

### **Types Of Advanced Prostate Cancer**

Advanced prostate cancer covers a range of disease. Some advanced cancer patients have metastases, others have no metastases seen on imaging tests, but their PSA rises after initial treatment, a condition known as rising-PSA or PSA-only prostate cancer. Almost all prostate cancers are adenocarcinomas and develop from the cells that make some of the fluid in semen.

Prostate cancer is often grouped into four stages, with stages III and IV being more advanced prostate cancer. (*See the diagram on page 36*) Although metastatic prostate cancer is not curable, treatment can often help to control the cancer for prolonged periods of time. This can help to reduce symptoms and improve the quality of life.

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.

Within Stage IV, there are several types of advanced prostate cancer:

#### **Biochemical Recurrence**

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

#### **Castration-Resistant Prostate Cancer (CRPC)**

CRPC means the 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 5 treatment (ADT) and can help lower your natural testosterone level. It is given through medicine or surgery to most men with 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, the prostate cancer is considered CRPC.

#### Non-Metastatic Castration-Resistant Prostate Cancer (nmCRPC)

nmCRPC is prostate cancer that no longer responds to hormone treatment and is only found in the prostate. It's discovered by a rise in the PSA level, while the testosterone level stays low. In addition, imaging tests do not show signs the cancer has spread.

#### Metastatic Prostate Cancer

When cancer cells have spread beyond the prostate, this is referred to as Metastatic Prostate Cancer. Cancer spread can be seen on 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 very common to be diagnosed with metastatic prostate cancer on first diagnosis, but it does happen.

Metastatic Hormone-Sensitive Prostate Cancer (mHSPC) 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 ADT, may be used to reduce the levels of these hormones.

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

Metastatic Castration-Resistant Prostate Cancer (mCRPC) is when cancer has spread past medical or surgical castration.

### **Testing For Diagnosis Of Advanced Prostate Cancer**

Advanced cancer may be found before, at the same time, or later than the main prostate tumor. Most men 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 the cancer has spread. Even if you have already been diagnosed with prostate cancer, your health care provider may want to observe changes over a period of time. For more in-depth guidance on understanding your diagnosis, please reference: Section 1: You and Your Prostate or Section 3: Understanding Your Diagnosis & Treatment Approach.

#### Tests to diagnose and track prostate cancer

**Blood Tests** — The PSA blood test measures a protein in your blood called the prostate-specific antigen (PSA). PSA is a protein produced by both cancerous and noncancerous tissue in the prostate. Only the prostate and prostate cancers make this protein. 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 prostate-specific antigen (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 doctor may want to test the level of testosterone in your blood.

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

**Biopsy** — A prostate biopsy involves using thin needles to take small samples of tissue from the prostate. The tissue is then looked at under a microscope to check for cancer. If cancer is found, the biopsy results will show how aggressive it is - in other words, how likely it is to spread outside of the prostate. A biopsy can pick up a faster growing cancer at an early stage when treatment may prevent the cancer from spreading to other parts of the body.

In many hospitals you may have a magnetic resonance imaging (MRI) scan (see Imaging and Scans Section on page 12), before having a biopsy. In other hospitals you may have a biopsy first. There are two main types of prostate biopsy.

Trans-rectal ultrasound (TRUS) guided biopsy: This is the most common type of biopsy. A thin needle is used to take small samples of tissue from the prostate.

You'll lie on your side on an examination table, with your knees brought up towards your chest. The doctor or nurse will put an ultrasound probe into your back passage (rectum), using a gel to make it more comfortable. The ultrasound probe scans the prostate, and an image appears on a screen. The doctor or nurse uses this

image to guide where they take the cells from. If you've had an MRI scan, the doctor or nurse may use the images to decide which areas of the prostate to take biopsy samples from.

You will have an injection of local anesthetic to numb the area around your prostate and reduce any discomfort. The doctor or nurse then puts a needle next to the probe in your back passage and inserts it through the wall of the rectum into the prostate. They usually take 10 to 12 small pieces of tissue from different areas of the prostate. But, if the doctor is using the images from your MRI scan to guide the needle, they may take fewer samples.

The biopsy takes 5 to 10 minutes. After your biopsy, your doctor may ask you to wait until you've urinated before you go home. This is because the biopsy can cause the prostate to swell, so they'll want to make sure you can urinate properly before you leave.

**Transperineal biopsy:** This is where the doctor inserts the biopsy needle into the prostate through the skin between the testicles and the rectum, called the perineum.

A transperineal biopsy usually takes about 20 to 40 minutes and is normally done under general or local anesthetic, so you will be asleep and won't feel anything. A general anesthetic can cause side effects - this should be explained to you before you have your biopsy.

The doctor will put an ultrasound probe into your rectum, using a gel to make this more comfortable. An image of the prostate will appear on a screen, which will help the doctor to guide the biopsy needle. If you've had an MRI scan, the doctor may just take a few samples from the area of the prostate that looked unusual on the scan images. This is known as a targeted biopsy.

Your healthcare team could decide to take up to 25 samples from different areas of the prostate. You may hear this called a template biopsy which is sometimes used if a TRUS biopsy hasn't found any cancer, but the doctor still thinks there might be cancer.

If you've had a general or local anesthetic, you will need to wait a few hours to recover before going home. And you will need to get someone to drive you home. Your healthcare provider may ask you to wait until you've urinated. This is because the biopsy can cause the prostate to swell, so they'll want to make sure you can urinate properly before you leave.

### **Imaging and Scans for Metastasis Cancer**

Imaging tests can help show if the cancer has spread to the lymph nodes or bones. If your PSA test are high, your doctor will likely order a transrectal ultrasound (TRUS) to view the prostate more closely. In addition, a biopsy may be done to confirm cancer (see previous section on page 11).

If your life expectancy is more than 5 years or you have cancer symptoms, testing for metastases may help with treatment planning. Signs of metastases are listed in the following section Signs of Advanced Prostate Cancer & Managing Symptoms. If you have these signs, you may get a bone scan, CT scan (computed tomography) or MRI scan (Magnetic resonance imaging) of your pelvis. Your doctor may change the rating of the cancer stage based on these tests results.

Some types of imaging and scans are:

Trans-rectal ultrasound (TRUS): A transrectal ultrasound (TRUS) helps your doctor to view the prostate more closely. You'll lie on your side on an examination table, with your knees brought up towards

your chest. The doctor or nurse will put an ultrasound probe into your back passage (rectum), using a gel to make it more comfortable. The ultrasound probe scans the prostate and an image appears on a screen. The doctor or nurse uses this image to better view the prostate gland.

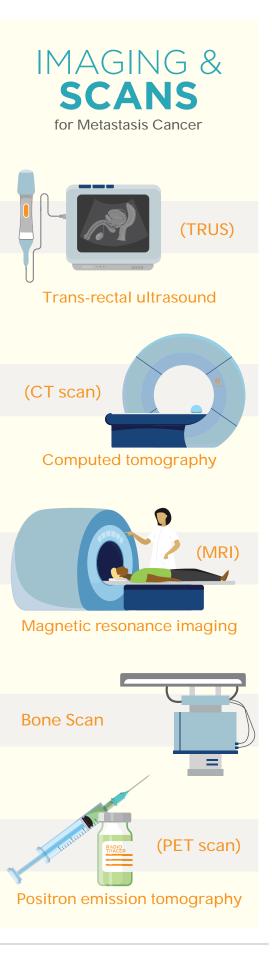
#### Computed tomography (CT) scan: CT of your

pelvis will show if your lymph nodes are enlarged. A computed tomography scan (CT) is a medical imaging technique used to obtain detailed internal images of the body. A CT scan takes many pictures of a body part from different angles using x-rays. A computer combines all the x-rays to make detailed pictures. Before the CT, you may need to drink enough liquid to have a full bladder. A full bladder helps to keep the bowel away so the prostate can be better seen. During the scan you will lie face up on a table. The table will move through the imaging machine. As the machine takes pictures, you may hear buzzing, clicking or whirring sounds.

Magnetic resonance imaging (MRI): A Magnetic resonance imaging (MRI) is a medical imaging technique using strong magnetic fields, magnetic field gradients, and radio waves to generate images of the anatomy and the physiological processes of the body. MRI scans may be carried out for a variety of reasons and will be accordingly targeted at specific zones of the body. Because of the powerful magnetic field involved, patients mustn't bring any metal into the scan. There are no exceptions to this rule. A person will probably be unable to have an MRI if they have any metal inside their body, such as bullets, shrapnel, or other metallic foreign bodies. This can also include medical devices, such as cochlear implants, aneurysm clips, and pacemakers.

The scanner itself typically resembles a large tube with a table in the middle, allowing the patient to slide in. Individuals who are anxious or nervous about enclosed spaces should tell their doctor. Often medication can be given prior to the MRI to help make the procedure more comfortable. The MRI scan is likely to last roughly 45 minutes to an hour for each body part that needs imaging. Patients will sometimes receive an injection of intravenous (IV) contrast liquid to improve the visibility of a particular tissue that is relevant to the scan.

Once in the scanner, the MRI technician will communicate with the patient via the intercom to make sure that they are comfortable. They will not start the scan until the patient is



ready. During the scan, it is vital to stay still. Any movement will disrupt the images, much like a camera trying to take a picture of a moving object. You will remain flat on your back and motionless throughout, and you may also have to hold your breath for up to 30 seconds while certain body parts are being photographed. Loud clanging noises will come from the scanner, for this reason earplugs or headphones may be provided to block out the loud noises of the scanner. This is perfectly normal.

After the scan, the radiologist will examine the images to check whether any more are required. If they are satisfied, the patient can go home. A report will be prepared for the requesting doctor. Patients are usually asked to make an appointment with their doctor to discuss the results.

**Bone Scan:** If prostate cancer spreads other sites of the body, it often goes to the bones first. A bone scan is advised if you have signs of symptoms of bone metastases. A bone scan can show whether areas of your bones have been weakened. The areas that show up on a scan are sometimes called 'hot spots'.

For this test, a special drug (called a radio-tracer) will be injected into your vein. The most common radiotracer used for bone scans is technetium. A special camera will then take pictures of the dye in the bones. The radio tracer can be seen in your bones 2 to 3 hours after it is injected. You may be asked to drink water and empty your bladder to wash out any of the radio-tracer that is not in your bones.

Areas of bone repair take up more of the radio-tracer than healthy bone and thus show up as bright or "hot" spots in the pictures. However, other health conditions besides cancer can cause bone repair. A radiologist can often tell what is and is not cancer in an abnormal scan.

**Positron emission tomography (PET) scan:** The PET scan may help your doctor better see where and how much the cancer is growing. A radio-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 allows your doctor to better see where and how much the cancer is growing.

### Signs Of Advanced Prostate Cancer & Managing Symptoms

The symptoms you have will depend on the cancer stage of your disease. Men with advanced prostate cancer may or may not have any signs of sickness. Symptoms will depend on the size of the new growth and the distance 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 men may experience extreme fatigue, feel weak or lose weight. When prostate cancer spreads to bones, there may be bone pain. It is possible to have few symptoms that might not affect you on a regular basis. If cancer spreads further over time, symptoms may affect you more. Speak to your healthcare provider if you have any pain or symptoms. There are treatments available to help manage them.

Your healthcare team may schedule office visits for tests and follow-ups over time. There are certain symptoms your doctor should know about right away, such as blood in your urine or bone pain, but it is best to ask your healthcare team about the symptoms you should report. Some men find it helpful to keep a "Symptoms and Pain diary" to help remember things to address during follow-up visits.

**Fatigue** — a feeling of extreme tiredness that doesn't go away, even if you're rested. This is very common in men with advanced prostate cancer. Fatigue is more extreme than normal tiredness. Normal tiredness will affect you if you've had a long workday, exercised, or participated in manual labor, or if you are suffering from lack of sleep. Unlike fatigue, normal tiredness will wane once you've rested. In addition, fatigue can also affect your mood. Making you feel sad, anxious, or depressed. You may feel guilty or frustrated that you can't live your life as you normally would. It can also affect the relationships with your family and friends. Many are surprised by how exhausting fatigue can feel and the impact it has on their lives.

### FATIGUE CAN MAKE IT DIFFICULT TO DO SOME THINGS, INCLUDING:

- everyday tasks getting dressed, having a shower or preparing food
- social activities, seeing friends and family
- sleeping (insomnia)
- concentrating
- remembering things
- understanding new information and decision making

### FATIGUE CAN BE CAUSED BY MANY FACTORS, SUCH AS:

- progression of prostate cancer
- treatments for prostate cancer
- stress, anxiety, or depression
- symptoms of advanced prostate cancer, such as pain or anemia
- other health problems
- not sleeping well
- lack of physical activity

### WHAT CAN HELP?

There are lots of things you can do to improve or manage your fatigue. Small changes to your life can make a big difference.

- being as physically active as you can this can help improve your energy levels, sleep, mood and overall health
- therapy getting help with emotional imbalances
- planning activities for your energy peaks maybe first thing in the morning,

or in the afternoon after a rest

- making time to rest and relax
- dealing with any sleep issues try to relax before bed avoid drinks with caffeine, such as tea and coffee that will keep you awake

### SIGNS OF ADVANCED PROSTATE CANCER

Be sure to read the full section to better understand how to manage your advanced prostate cancer symptoms.



- eating a well-balanced diet balancing your overall mental and physical wellness
- trying complementary therapies alongside your usual treatment
- asking for help if you need it, for example with shopping or jobs around the house

Eating problems and weight loss — Many men with advanced prostate cancer have problems eating, or report not feeling very hungry. Nausea and vomiting are also possible symptoms. These problems could be caused by the cancer or by the treatments. Worry and stress about your circumstances can also affect your appetite. Eating issues or loss of appetite can lead to weight loss - increasing exhaustion and weakness. Advanced prostate cancer can also cause weight loss because it changes the way the body uses energy.

### WHAT CAN HELP?

There are lots of things you can do to improve or manage your eating routine. Small changes to your life can make a big difference.

- if sickness due to treatment is an issue your doctor can give you anti-sickness drugs
- steroids can also increase your appetite and are sometimes given along with other treatments
- eat small amounts often, if you're struggling to eat because of nausea, try to avoid strong smelling foods; Cold foods tend to smell less, or it may help if someone cooks for you; eat when you feel less sick, even if it's not your usual mealtime
- fatty and fried foods can make sickness worse; drink plenty of water - drink slowly and try not to drink too much before you eat
- alert your healthcare team if you lose weight; they can refer you to a dietitian who can provide advice about high calorie foods and any supplements that might help

**Pain** — is a common problem for men with progressive prostate cancer, although many have no pain at all. Cancer can cause pain in the areas it has spread into. If you are experiencing pain, usually it can be relieved or reduced, with the right treatment and management.

Pain is most common when the cancer has spread to the bones. Cancer can damage or weaken the bone, which may cause pain. But not all men with cancer in their bones report bone pain. Be sure to alert your healthcare team to any pain, it's best they are aware of all symptoms a patient may be having.

Bone pain is a very specific feeling. Men describe it as feeling like a toothache but in the bones — like a dull aching or stabbing sensation. It can worsen when you move, and the area may become tender to touch. Every man's experience will be different. The pain may be constant, or it might come and go. The scale of pain can also vary and depends on where the affected bone is.

There are other types of pain in the cancer journey as well. For example, if the cancer presses on a nerve, this can also cause pain — a shooting, stabbing, burning, tingling or numbness. Pain can also be a symptom of a more serious condition called Metastatic Spinal Cord Compression (MSCC). (See the MSCC care section of the guide on page 24)

### WHAT CAN HELP?

By adjusting or combining treatments, pain from cancer is usually managed well. It's not necessary to have to accept pain as a normal part of the cancer journey. If you have pain, speak to your healthcare team. The earlier pain is treated, the easier it will be to control.

- check with your healthcare provider on what treatments can be done to relieve pain with complementary therapies
- getting emotional and mental support
- treatments for other causes of pain, ex. antibiotics to treat infection
- keeping a "Symptoms and Pain diary" to help describe the experiences
- eating a healthy diet and doing regular gentle exercise such as yin yoga or strolling
- To find the best way to deal with your pain, you might have a pain assessment and be referred to a palliative care specialist. Palliative care specialists provide treatment to manage pain and other symptoms of advanced cancer.

**Urinary problems** — A patient could experience urinary problems if the cancer is pressing on the urethra or has spread to areas around the prostate or bladder. Urinary problems can also occur when there is an infection or an enlarged prostate. Additional issues include pain or difficulty urinating, an urgency to urinate, and hematuria (blood in the urine); these may be more common after radiation therapy for prostate cancer.

A large proportion of men experience urinary issues in association with surgery or external beam radiation therapy (EBRT). The most common urinary issue after surgery is incontinence, or the inability to control the flow of urine from the bladder. Generally, the degree of incontinence will improve over the first year following surgery, but some men may be left with a permanent problem. There are procedures (ex. slings and artificial urinary sphincter implants) that can help men with permanent or bothersome urinary incontinence.

**Problems emptying your bladder:** If the cancer is pressing on your urethra or the opening of your bladder, you may find it difficult to empty your bladder fully. This can sometimes cause urine retention, where urine is left in your bladder when you urinate.

Acute urine retention: This is when you suddenly and painfully can't urinate at all - it needs treating straight away. Acute retention isn't very common in men with advanced prostate cancer. But if it happens, call your healthcare provider, or go to your nearest emergency room or urgent care. They may need to drain your bladder using a catheter.

Leaking urine (incontinence): Cancer can grow into the bladder and the muscles that control urination, making the muscles weaker. This could mean you leak urine or need to urinate urgently.

**Blood in your urine:** Some men notice blood in their urine (hematuria). This may be caused by bleeding from the prostate. It can be alarming but can usually be managed. Contact your urologist immediately if this is a symptom you are experiencing.

### WHAT CAN HELP?

By adjusting treatments, or combining treatments, pain from cancer is usually managed well. It's not necessary to have to accept pain as normal part of the cancer journey. Treatment options will depend on what urine issues are present and what treatments are suitable for each situation. Ask your healthcare team what solution is best.

- use absorbent pads and pants to manage leaking urine
- kegel exercises help in strengthening the muscles of the pelvic region, also helpful in strengthening the urinary bladder; beneficial for frequent urination
- if you find you need to rush to the toilet a lot and sometimes leak before you get there, find out where there are public toilets before you go out
- drink plenty of water
- do not drink excess caffeine and alcohol
- medicines called anti-cholinergic relax the bladder and help relieve symptoms of overactive bladder and reduce episodes of urge incontinence

**Kidney problems** — The kidneys remove waste products from your blood and produce urine. Prostate cancer can block the tubes that carry urine from the kidneys to the bladder (ureters), which affects how well the kidneys work. Prostate cancer and some treatments can also make it difficult to empty the bladder (which can lead to urine retention). This can stop the bladder and kidneys from draining properly, which can cause kidney issues. Severe kidney problems can lead to high levels of waste products in your blood, which can be harmful.

### SYMPTOMS INCLUDE:

- tiredness and lack of energy
- feeling sick

- swollen ankles and feet
- poor appetite

#### WHAT CAN HELP?

- a blood test can check how well your kidneys are working
- a tube inserted into the kidney to drain urine into a bag outside your body (nephrostomy)
- a stent put inside one or both ureters to allow urine to flow from the kidney to the bladder

**Bowel Dysfunction Fecal incontinence** — (also referred to as bowel dysfunction) is the inability to control defecation (bowel movements). Men with advanced prostate cancer can get bowel problems for a variety of reasons. Patients who undergo radiation therapy, especially external beam radiation therapy (EBRT) may experience bowel problems. These issues may occur during treatment or can develop months or years later. But typically, this a short-term side effect and less common in the modern era of radiation treatment.

### OTHER FACTORS THAT AFFECT THE BOWELS INCLUDE:

Pain-relieving drugs such as morphine and codeine can cause constipation. Don't stop taking them but speak to your healthcare provider if problems arise.

Becoming less active, changes to your diet, and lack of fluid intake can also cause constipation. Be sure to keep your body hydrated and move your body when you can.

You may also get bowel problems if prostate cancer spreads to your lower bowel (rectum), but this is rare. If it happens, it can cause symptoms including constipation, pain, bleeding and, rarely - being unable to empty the bowels at all.

Problems emptying your bowels or leaking from your back passage might sometimes be caused by a condition called metastatic spinal cord compression (MSCC). But this is rare. (See the MSCC care section of the guide on *page 23)* 

#### SYMPTOMS INCLUDE:

- passing more wind than usual, which may sometimes be wet (flatulence)
- passing loose and watery bowel movements (diarrhea)
- difficulty emptying your bowels (constipation) or a feeling that your bowels haven't emptied properly
- needing to empty your bowel more often, or having to rush to the toilet (fecal urgency)
- pain in your abdomen (stomach area) or back passage
- being unable to empty your bowels (bowel blockage)
- leaking from your back passage this is very rare

• kidney problems caused by urine retention can be eased with a catheter to drain urine from the bladder

#### WHAT CAN HELP?

- Lifestyle changes Changes in diet could help with many bowel problems. Your healthcare provider might refer you to a dietitian, who can help you make changes to your diet. Please visit the resources center at fightingprostatecancer.org where you will find recipes, shopping lists and strategies for healthy living.
- **Constipation relief** eating lots of high fiber foods help. Fruit such as prunes, apples, and pears as well as whole grain bread, whole grain breakfast cereals and porridge will loosen the stool. Gentle exercise such as going for a walk can also help with constipation.
- **Drink plenty of water** Aim for about eight glasses of water a day.
- **Diarrhea relief** avoiding spicy food and eating fewer dairy products, such as milk and cheese, may also help. Make sure you drink lots of water or electro-light replacement to replace the liquid the body has lost.
- **Medicines or treatments** If you have constipation, your healthcare team can prescribe gentle laxatives to help you empty your bowels. If you have constipation or bowel obstruction caused by prostate cancer, they might recommend radiotherapy to the bowel.
- **Blocked bowels** you may need to have surgery this is rare.

**Sexual problems** — Dealing with advanced prostate cancer can have an impact on your sex life. There are lots of different reasons why this might happen. For example, hormone therapy can reduce the desire for sex (libido) and can affect the ability to get or keep an erection. Past treatments, such as surgery or radiotherapy, can also cause erection problems. Feeling depressed, worry-full, anxious, or weak can affect your sex life too.

**Erectile dysfunction** — Following surgery or radiation therapy, as well as during hormonal therapy, most prostate cancer patients experience some degree of erectile dysfunction (ED) - the inability to attain and/or maintain an erection that is sufficient for satisfying sexual activity. Surgical nerve-sparing techniques used during surgery can reduce some of this side effect, but it is common for at least some degree of ED to be present after treatment. If ED becomes a problem, your doctor can prescribe medications that can be helpful for some patients.

Loss of fertility — Loss of natural fertility and ejaculation is an unavoidable side effect of radical prostatectomy, as well as in association with radiation therapy and chemotherapy. Due to disruption of normal semen production and ejaculation, loss of fertility is an issue many men face in the journey of prostate cancer. Hormone therapies such as ADT and particularly surgical castration also produce complete infertility. For this reason, prostate cancer patients who wish to father children in the future may elect to bank their sperm. Talk with your healthcare team for options and treatments available in the area of fertility.

### WHAT CAN HELP?

• Treatments for erection problems include tablets, vacuum pump, injections, pellets, and cream. Because getting an erection also relies on your thoughts and feelings, tackling any worries or relationship issues as well as having medical treatment can help. Speak to your GP, nurse or doctor for options offered for treatment or a referral to a specialist service.

- Hormone therapy can cause a loss of desire for sex (libido), this might not come back quickly. There are treatments that may still help with erections, even if desire for sex is low. Your sex drive may improve while you're not having hormone therapy. But it can take several months, and some men don't notice any improvement.
- An active sex life before a diagnoses of prostate cancer is unlikely to be the same during the cancer journey. Support dealing with these changes is available. There are still many ways to have pleasure, closeness, and fun. If you have a partner, talking about sex, your thoughts and feelings can help you both deal with any changes. If you are in a relationship, you may need time alone together.
- If you have a catheter to help manage urinary problems, it is still possible to have sex. Speak to your healthcare team about this.

**Broken bones (fractures)** — The most common place for advanced prostate cancer to spread to is the bones. Cancer can damage bone structure, making them weaker. And certain types of hormone therapy can also make your bones weaker, also known as bone thinning. If bone thinning is severe, it can lead to a condition called osteoporosis. This increases the risk for broken bones (fractures).

Damage to the bones can make it difficult or painful to move around. You may not be able to do some of the things that you are accustomed to, because you're in pain, or because you are more likely to break or fracture a bone.

### WHAT CAN HELP?

- You might be given radiation therapy to slow down the growth of the cancer. This can aid in the control of damage to the bones and relieve bone pain. A treatment option might be drugs called bisphosphonates, which can strengthen the bones and help prevent broken bones. Bisphosphonates are also used to treat pain caused by cancer that has spread to the bones. (See the Treatment Options section on page XX)
- If an area of bone is badly damaged, surgery may be needed to repair it. A metal pin or plate is put inside the bone to strengthen it and reduce the risk of it breaking. Another option is a type of cement can be used to fill the damaged area. Surgery isn't suitable for all men with advanced

### TIPS FOR EASE & COMFORT

when experiencing symptoms



### ALLOW YOUR BODY TO **REST & RECOVER**



### **GENTLE EXERCISE**



DO NOT FAT FATTY OR FRIED FOODS CUT OUT EXCESS **CAFFEINE & ALCOHOL** 



prostate cancer. Treatment options depend on where the damaged bone is, and other factors in regard to your health and strength. If you have an operation, you may have radiation therapy afterwards to stop the cancer growing in that area.

• Even though physical activities may be limited, staying active will help with your overall health and wellness, as well as your ability to move around. It will aid in keeping you strong and help prevent falls that could cause broken or fractured bones. Speak to your healthcare team about what activity options are realistic in your specific circumstance.

**Lymphedema** — If the cancer spreads into the lymph nodes it could lead to a condition called lymphedema – occurs when there is a blockage in the lymphatic system. The lymphatic system is part of the body's immune system. It carries lymph fluid around your body. If it is blocked, the fluid can build up and cause swelling (lymphedema). Prostate cancer itself, as well as some treatments such as surgery or radiation therapy, can cause the blockage. This can happen months or even years after treatment.

Lymphedema in prostate cancer usually affects the legs, but can affect other areas, including the penis or the skin around your testicles (scrotum).

Lymphedema can affect daily life. Patients who suffer from this might be less able to move around and find it more challenging to carry out everyday tasks. Some men worry about the appearance of the affected area, and some feel anxious about others seeing it.

### SYMPTOMS INCLUDE:

- swelling
- pain, discomfort, or heaviness
- inflammation, redness, or infection
- tight or sore skin

### WHAT CAN HELP?

If are experiencing any of the above symptoms contact your healthcare team. There are treatments that can help to manage them. Treatments aim to reduce or stop the swelling and make the patient more comfortable. They are most effective if started when the symptoms first present. If you have lymphedema, you may be referred to a lymphedema specialist, who can teach management of the swelling. Living with lymphedema can be difficult. If you need support, speak to your healthcare team, who could refer you to a specialist or therapist. There are also a variety of other things that might help.

- **Skincare** Caring for the skin, such as regular cleaning and moisturizing, can help to keep the skin organ soft and reduce the chance of it becoming cracked and infected.
- Manual lymphatic drainage Special massage can help to increase the flow of lymph fluid. Your healthcare provider can show you, a partner, a family member, or a friend how to do this.
- **Gentle exercise** may help to improve the flow of lymph in the affected area of the body. For example - simple leg movements, similar to those recommended for long flights, may help with leg lymphedema.

• **Compression bandages or stockings** — Wearing close-fitting underwear or Lycra cycling shorts may help control any swelling in your penis or scrotum. As well as, using compression bandages or stockings can help to encourage the lymph fluid to drain from the affected area.

Anemia — a condition in which a person lacks enough healthy red blood cells to carry adequate oxygen to the body's tissues. The most common causes of anemia include nutritional deficiencies, particularly iron deficiency, though deficiencies in folate, vitamins B12 and A, can also contribute — this is known as vitamin deficiency anemia. Some infection diseases: such as, prostate cancer, malaria, tuberculosis, HIV, and parasitic infections can also cause anemia. There are many forms of anemia, each with its own cause. It can be temporary or long term and can range from mild to severe. In most cases, anemia has more than one cause. Sometimes anemia is caused by not enough iron in your diet. You might be more at risk of this if you have loss of appetite or issues with your diet. See your healthcare provider if you are at risk or suspect that you have anemia. It can be a warning sign of a more serious illness.

Some men with advanced prostate cancer can develop anemia. This is caused by a drop in the number of red blood cells and can happen when your bone marrow is damaged - either by the prostate cancer or by treatment such as hormone therapy, chemotherapy, or radiation therapy.

Anemia signs and symptoms vary depending on the cause and severity of anemia. Depending on the causes, you might have no symptoms. At first, anemia can be so mild that you don't notice it. But symptoms worsen as anemia worsens.

#### SYMPTOMS INCLUDE:

- Fatigue
- Weakness
- Pale or yellowish skin, dry skin, or easily bruised skin
- Irregular heartbeats
- Shortness of breath
- Dizziness or lightheadedness
- Chest pain
- · Cold hands and feet
- Headaches
- Sore tongue
- Unintended movement in the lower leg (restless legs syndrome)

#### WHAT CAN HEIP?

If you are experiencing symptoms of anemia, you will need to have a blood test to check your red blood cell levels. Which treatment you're offered will depend on what's causing your anemia.

Your urologist may recommend you take iron supplements to help with anemia. This can cause bowel problems such as constipation or diarrhea - see previous section for ways to manage this. If your red blood cell levels are very low, you may need a blood transfusion. This can be a quick and effective way of treating anemia.

- Avoid iron deficiency anemia and vitamin deficiency anemias by eating a diet that includes a variety of vitamins and minerals, including Iron, Folate, Vitamin B-12, Vitamin C. Iron-rich foods include beef and other meats, beans, lentils, iron-fortified cereals, dark green leafy vegetables and dried fruit.
- Get a good night sleep. Rest and recovery are important for the body to heal.
- It might be necessary to stall further cancer treatment until the anemia is improved by iron, blood transfusions, getting necessary B vitamins and/or drugs to stimulate your body to produce EPO. The healthcare team will advise if this is the right course of treatment.

**Metastatic spinal cord compression (MSCC)** — happens when cancer cells that have spread from the prostate grow in or near to the spine, and press on the spinal cord. MSCC isn't common, but it is important to be aware of the risk if prostate cancer has spread to your bones or has a high risk of spreading to your bones. The risk of MSCC is highest if the cancer has already spread to the spine. Speak to your healthcare team for more information about your specific risk.

Below symptoms can also be caused by other conditions, but it's very important to seek medical advice immediately if you suspect you might have MSCC. Don't wait to see if it gets better and don't worry if it's an inconvenient time, such as the evening or weekend. If you are diagnosed with MSCC, you should start treatment as soon as possible - ideally within 24 hours. MSCC could affect your ability to walk and move around if it isn't treated quickly. Getting treatment early can reduce the risk of long-term problems.

### SYMPTOMS INCLUDE:

- Pain or soreness in the lower, middle, or upper back or neck. Pain may be immediately severe or get worse over time. It might feel intense when coughing, sneezing, lifting, or straining, or going to the bathroom. It might get worse when lying down. It may cause interruption in sleep, or no sleep at all.
- Pain is described as a narrow band of pain around the abdomen (stomach area) or chest that can move towards your lower back, buttocks, or legs.
- · Weakness or loss of control of the limbs, or difficulty standing or walking. Feelings of unsteadiness on your feet or as if your legs are giving way are reported, and others report clumsiness.
- Numbness or tingling (pins and needles) in the legs, arms, fingers, toes, buttocks, stomach area or chest, that persists and doesn't go away.
- Problems controlling the bladder or bowel. Trouble emptying the bladder or bowel, or no control over them.

### WHAT CAN HELP?

- If you have been diagnosed with MSCC, this means your cancer is advanced. MSCC itself doesn't affect how long you will live. But it could affect your ability to walk and move around if it isn't treated quickly. Treatment ideally is started within 24 hours.
- **Steroids** usually high doses of a steroid (dexamethasone) are given to the patient as soon as the diagnosis

is made. A mix of steroid injections and tablets may be prescribed. This helps reduce pressure and swelling around the spinal cord. It can also quickly relieve symptoms such as pain.

- radiation therapy starts as soon as possible after MSCC is diagnosed.
- your circumstance.
- cancer.
- strengthen bones.

**Hypercalcemia** — is a condition in which the calcium level in your blood is above normal. Calcium is usually stored in the bones, but the cancer can cause calcium to leak into the blood. Too much calcium in your blood can weaken your bones, create kidney stones, and interfere with how the heart and brain work. It is very rare, but this condition can sometimes affect men with advanced prostate cancer. If it happens, it's important to treat it so that you don't develop a more serious condition.

These symptoms can be quite common in men with advanced prostate cancer and might not be caused by hypercalcemia. Tell your healthcare provider if you have any of these symptoms. There may be some tests ordered to find out what is causing them, including a blood test to check the level of calcium in your blood. Hypercalcemia doesn't always cause symptoms, but it can cause the following:

SYMPTOMS INCLUDE:

- feeling and being sick (nausea and vomiting)
- drowsiness, tiredness, weakness, or lack of energy
- dehydration
- feeling more thirsty than usual
- confusion
- muscle spasms
- joint pain, bone pain or tenderness

• **External radiation therapy** — is the use of high-energy radiation to destroy cancer cells. It is the most common treatment for MSCC. It may be used on its own, or sometimes alongside other treatments such as surgery. It is given by directing radiation rays at the tumor from outside the body as a short course of treatment. This can range from one single treatment to one treatment a day for one or two weeks. External

• **Surgery** — is only suitable for a small number of people with MSCC. Whether you can have surgery depends on several things, including: the type of cancer you have, the area of the spine affected, how stable the spine is. The aim of surgery is to remove as much of the tumor as possible and relieve pressure on the spinal cord and nerves. Some people may have several parts of the vertebrae removed. Surgeons will aim to do this without weakening the spine, they may also use metal rods, screws or bone grafts to make the spine stable. Your healthcare team will explain the operation in more detail if surgery is an appropriate option for

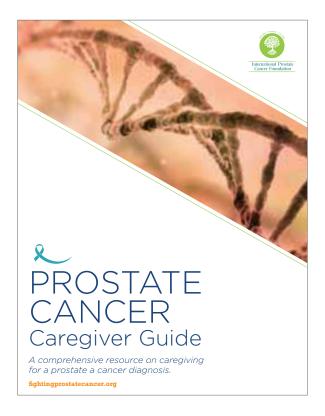
• Chemotherapy — is the use of anti-cancer drugs to destroy cancer cells. It is sometimes used to treat MSCC. It may be used for tumors that are very sensitive to chemotherapy, such as lymphoma or testicular

• **Other Drugs** — bisphosphonates, and another drug called denosumab, may sometimes be used to help

- irregular heartbeat
- loss of appetite
- pain in your lower stomach area
- difficulty emptying your bowels (constipation)
- needing to urinate often (frequency)

#### WHAT CAN HELP?

- A visit to the hospital might be necessary for a couple of days. Severe hypercalcemia that causes symptoms and requires a hospital stay may be treated with fluids through a drip in your arm. This will help to flush calcium out of your blood and bring your calcium levels down.
- Drugs called bisphosphonates can help treat hypercalcemia by lowering the level of calcium in your blood. They usually start to work in two to four days. If your blood calcium levels are still high, you may be given another dose of bisphosphonates after a week. You'll usually stop treatment once your calcium levels are back to normal.
- Once the calcium levels are back to normal, you'll have regular blood tests to check that the calcium levels stay low. Monitor to see if symptoms come back.



### For more information on caregiving for a prostate cancer patient please download the Prostate Cancer Caregiver Guide Volume II.

Visit the downloads section of the resources center to find volume 1 (prostate cancer) and 2 (caregiving for prostate cancer) patient guides as downloadable pdfs.

### www.fightingprostatecancer.org/ resources-1

## 3. UNDERSTANDING YOUR DIAGNOSIS

At the cellular level, prostate cancer happens because of changes to your body's genes that control the way its cells work, especially how they grow and divide. Genetic changes can be passed down from your family members, happen randomly, or happen because of an environmental exposure to something cancer-causing.

Most prostate cancers are adenocarcinomas, or cancers of gland cells. Some can spread quickly, but most are slow growing. Rarer types of prostate cancer include sarcomas, small cell carcinomas, neuroendocrine tumors and transitional cell carcinomas.

Typically, prostate cancer is diagnosed after closely examining biopsy cells through a microscope. There are several types of cells in the prostate, and each contributes in its own way to the prostate's development, architecture, and function. But cancer cells look different than normal prostate cells. Pathologists look for these differences first to detect the presence of cancer and then to determine the cancer "Grade" or Gleason Score.

Low-grade cancer cells tend to grow slowly, while high-grade cancer cells look abnormal and grow more quickly. For many years, the Gleason scoring system has been used for grading the tissue taken during a biopsy. All men with prostate cancer will have a Gleason score between 6 and 10. Your doctor will also consider how much cancer there is (its volume). For example, if you have one small area of cancer, your doctor would consider this a low-volume cancer. If you have a low-volume cancer that is also low grade, you might choose to have less aggressive management or treatment.

### **Early Diagnosis & Screening**

Prostate cancer can often be diagnosed early by testing for Prostate-Specific Antigen (PSA) levels in a man's blood. Another way to diagnose prostate cancer early is with the digital rectal exam (DRE) in which the doctor puts a gloved, lubricated finger into the rectum to feel the prostate gland.

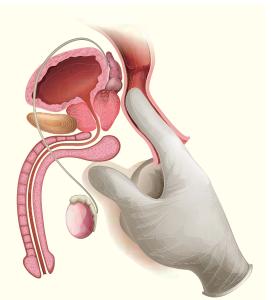
If the results of either one of these tests are abnormal, further testing is often done to see if a man has prostate cancer. If cancer is found as a result of screening with the PSA test or DRE, it will probably be at an earlier, more treatable stage than if no screening were done.

Neither the PSA test nor the DRE is 100% accurate. Doctors are studying if early detection tests will lower the risk of death from prostate cancer. The most recent results from 2 large studies were conflicting and didn't offer clear answers.

Early results from a study done in the United States found that annual screening with PSA and DRE did detect more prostate cancers than in men not screened, but this screening did not lower the death rate from prostate cancer.

A European study did find a lower risk of death from prostate cancer with PSA screening (done about once every 4 years), but the researchers estimated that about 570 men would need to be screened (and 18 diagnosed) to prevent one death from prostate cancer.

Prostate cancer is often a slow-growing cancer, so the effects of screening in these studies may become clearer in the coming years. Both studies are being continued to see if longer follow-up will give clearer results. Several other large studies of prostate cancer screening are currently going on as well.



### GET A DIGITAL RECTAL EXAM AND PSA TEST IF ...



African American

urination pain or pain in the back, hips or pelvis



There is no question that screening can help find many prostate cancers early, and the International Prostate Cancer Foundation recommends both the PSA and DRE.

### **Digital Rectal Exam**

Doctors use a DRE (digital rectal exam) to screen for cancer, rate the cancer stage, and assess treatment results. For this exam, your doctor will put a glove on his or her hand and then put lubricant on his or her index finger. Next, your doctor will insert a finger into your rectum to feel your prostate as shown in illustration. Your prostate can be felt since it is on the other side of the rectal wall. Bear in mind that not all parts of the prostate can be felt on this exam.

### **Should I Be Screened?**

The International Prostate Cancer Foundation recommends that men have a chance to make an informed decision with their healthcare provider about whether to be screened for prostate cancer. The decision should be made after getting all the facts about the uncertainties, risks, and potential benefits of prostate cancer screening.

It's important for each man to talk with his doctor about whether screening is right for him. There are many factors to consider, including age and health. If you're young and develop prostate cancer, it may shorten your life if it's not caught early. Those in the medical community who advocate regular screening believe that finding and treating prostate cancer early offers men more treatment options with potentially fewer side effects. Ultimately, decisions about screening should be individualized based on a man's level of risk, overall health, and life expectancy, as well as his desire for eventual treatment if he is diagnosed with prostate cancer.

### When To Start Screening ....

The right time to start screening is generally based on individual risk, with age 40 being a reasonable time to start screening for those at highest risk (genetic predispositions or strong family histories of prostate cancer at a young age). For otherwise healthy men at high risk (positive family history or African-American men), starting at age 40-45 is reasonable.

Guidelines differ for men of average risk. Some recommend a baseline PSA and DRE at age 40, and others recommend starting at age 50. In general, all men should create a proactive prostate health plan with their doctor that is right for them based on their lifestyle and family history. If no prostate cancer is found during screening, the time between future screenings depends on the results of the PSA blood test:

Men who have a PSA of less than 2.5 ng/mL may only need to be retested every 2 years. Screening should be done yearly for men whose PSA level is 2.5 ng/mL or higher.

fightingprostatecancer.org for resources in your area.

You can find a useful resource for making these decisions at the U.S. Centers for Disease Control and Prevention site. www.cdc.gov/cancer/dcpc/publications/prostate.htm

### **PSA Screening**

What is PSA? Prostate specific antigen (PSA) is a protein made by both normal prostate cells and cancerous prostate cells. PSA levels are measured using a blood test. The PSA test does not specifically test for cancer. A PSA reading above the typical range for your age may indicate the possibility of prostate cancer.

The amount of PSA in blood can be raised even when a man does not have cancer. Other factors can increase PSA levels, including benign prostate hyperphasia (BPH), recent sexual activity or an infection in the prostate. In addition, some men with prostate cancer have normal PSA levels.

Because PSA levels can be variable, your doctor will often use results from more than one blood test, over time, to help determine your risk of prostate cancer. Your doctor will also compare your PSA result against other men the same age as you.

**Screening and Biopsy** The prostate cancer death rate in the United States has been nearly halved since the beginning of prostate-specific antigen (PSA)-based screening over 25 years ago. A prostate cancer screening may reveal results that prompt a doctor to recommend a biopsy. There are many other supplementary tests and considerations that can help a man who is undergoing screening decide if a biopsy is necessary, including:

Lower vs. higher free PSA test

PSA velocity (rate of rise over time)

PSA density (PSA per volume of prostate)

Different forms of PSA (i.e. bPSA, pro-PSA) Family history

In general, a lower free PSA (percentage) indicates a higher risk of finding cancer at biopsy, as does a higher PSA velocity and PSA density. Once a man has a confirmed diagnosis of prostate cancer, rising PSA is a useful test to track prostate cancer growth, since it can be detected well before any clinical signs or symptoms. The PSA is also widely accepted as an invaluable tool for monitoring prostate cancer disease activity and remission from prostate cancer after treatment.

Where Can I Find Free Prostate Cancer Screening? Local hospitals and local prostate cancer support groups usually either offer screening or have a list of places you can go for screening. Visit the resources center at

Ethnicity

Prior biopsy findings

**Digital rectal exam results** 

### What Is A Biopsy?

A prostate biopsy is a diagnostic test in which a small needle is inserted into the prostate gland to obtain 12 to 14 tissue samples for further evaluation under a microscope. During a biopsy, small amounts of tissue are taken from different parts of the prostate. The samples are sent to a lab where a pathologist examines the tissue to see whether cancer cells are present. Multiple tissue samples are taken so that the pathologist can indicate the extent of the tumor in the prostate.

A biopsy is usually done with the help of a transrectal ultrasound (TRUS) probe. The ultrasound shows the shape and size of the prostate on a screen. The image helps guide the doctor to insert a thin, hollow needle into the prostate. The TRUS probe is inserted through the rectum (transrectal biopsy) or the skin between the anus and the scrotum (transperineal biopsy). Transperineal biopsies may allow better sampling of the whole prostate and reduce the risk of infection. However, the procedure takes longer, and is performed in an operating room under a general or local anesthetic. Recently, urologist have used MRI as a guide while doing TRUS biopsies, which has shown to increase the yield of biopsy. Ask your urologist if they recommend biopsy for you.

A biopsy can be uncomfortable and for a few days there may be a small amount of blood in your urine, semen or bowel movements. You may be given antibiotics to reduce the possibility of infection.

For more in-depth information on Biopsies, please reference: Section 2. Testing for Diagnosis of Advanced Prostate Cancer on page 11.

### **Prostate Cancer Biomarkers**

What is a prostate cancer biomarker? A biomarker specific for prostate cancer is a biological molecule found in blood, urine, or tissues that is related to the presence of prostate cancer. It is also referred to as a molecular marker or a signature molecule.

Why are prostate cancer biomarkers important? Prostate cancer biomarkers help to personalize each patient's care in the early detection, diagnosis, and treatment choices for prostate cancer. Through advanced science, researchers from many different institutions and companies have developed a variety of tests that look at each person's genes or biomarkers and help to determine individual risk for having prostate cancer, the need for biopsies or repeat biopsies, and the best course of treatment.

What are the most frequently used biomarker tests for prostate cancer and how are they used? Biomarkers have the following uses and benefits in each of the stages of prostate cancer screening and diagnosis:

Screening: Reduce the number of unnecessary (negative) biopsies performed as a result of elevated PSA levels

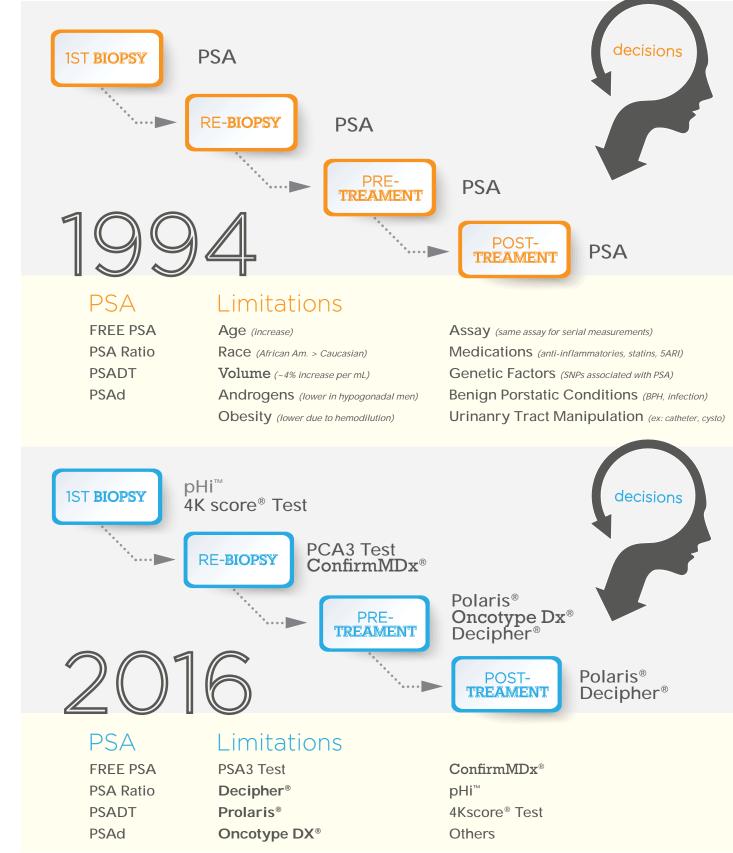
After a positive biopsy: Distinguish aggressive cancers that need treatment from non-aggressive ones that do not

After surgery: Determine if additional treatment is necessary

Currently, there are prostate cancer biomarkers in the following categories:

**Urine-based biomarkers.** The prostate sheds material that can be detected and measured in the urine. Urine tests can detect changes in genes and biomarkers that are specific to prostate cancer. The results of these new tests can help pinpoint whether a biopsy is necessary.

## **EVOLUTION OF PROSTATE CANCER BIOMARKERS**



**Tissue-based biomarkers.** These tests use tissue from the prostate to look for specific gene markers that can help doctors distinguish between slow-growing and more aggressive forms of prostate cancer. These tests can even detect hidden cancers in men whose biopsies were negative.

**Blood-based biomarkers.** Cancer spreads when tumor cells break away, get swept up into the bloodstream, and start to grow in other parts of the body. These "liquid biopsies" use blood tests to capture and measure circulating tumor cells or proteins to diagnose and/or treat prostate cancer.

### **Genomic Tools**

Genomic tests measure the expression of genes that might influence the aggressiveness of your prostate cancer. These tests are playing an increasingly important role in the management of prostate cancer at all phases: from diagnosis to management decisions to post-treatment decisions about supplemental treatment.

Information from genomic tests can help guide decisions about the best management for your specific disease. For example, genomic tests might be done after PSA screening to judge whether high PSA levels indicate cancer; after a biopsy to gauge whether the biopsy is an accurate reflection of the prostate tumor; or after surgery, to determine the likelihood of the cancer coming back.

**Oncotype DX® Genomic Prostate Score** One such genomic test, the Oncotype DX Genomic Prostate Score (GPS), is intended for men recently diagnosed with very low-risk, low-risk, and select cases of intermediate-risk prostate cancer. The Oncotype DX GPS examines expression of specific genes in the prostate tumor to help predict the likelihood of high-risk disease not detected through a biopsy. The information provided by the Oncotype DX prostate cancer test is used in conjunction with the NCCN risk groups and may help you and your doctor determine the most appropriate management option for you based on the biology of your individual cancer.

SelectMDx® A non-invasive urine test ("liquid biopsy"), SelectMDx measures the expression of two mRNA cancer-related biomarkers (HOXC6 and DLX1). The test provides binary results that, when combined with the patient's clinical risk factors, help the physician determine whether the patient may benefit from a biopsy and early prostate detection, or whether the patient can avoid a biopsy and return to routine screening

**ConfirmMDx®** A tissue test to improve the identification of men at risk for undetected clinically significant prostate cancer. Independently published clinical studies have shown that for men who have received a negative prostate biopsy result, ConfirmMDx is the single most significant predictor of patient outcome among all currently available clinical factors, such as age, PSA level, and DRE results. This test can rule in high-risk men who have had a previous negative biopsy result, may be harboring undetected cancer (a false-negative biopsy result), and therefore may benefit from a repeat biopsy and appropriate treatment, or rule out cancer-free men from undergoing unnecessary repeat biopsies and screening procedures, helping to reduce complications, patient anxiety, and excessive healthcare expenses associated with these procedures.

**Other Genomic Tests** There are other genomic tests available such as \*Decipher3 and \*Prolaris4 that assess tumor aggressiveness. Both Decipher and Prolaris are available for patients who have already gone through a radical prostatectomy (surgical removal of the prostate) and in men who have had a biopsy that shows prostate cancer. These tests are validated as predictors of outcomes in prostate cancer but were not developed specifically for very low-risk, low-risk, and low intermediate-risk prostate cancer patients. Ask your physician about the best test option for you.

## **GLEASON GRADES**

To obtain a Gleason score, doctors first assign the cancer two Gleason grades. The grades are combined to obtain a Gleason score. Gleason grades range from 1 to 5.



(1)	signs of cancer.
2	Glands are larger and have more sp
3	Glands are even further apart, are c
4	There are hardly any glands. Cance Clumps of cancer cells are invading
(5)	Often, there are no glands. There are

### **Understanding The Numbers**

**Gleason Grading** The Gleason grading system accounts for the five distinct patterns that prostate tumor cells tend to go through as they change from normal cells to tumor cells. The higher the Gleason score, the more aggressive the cancer and the more likely it is to metastasize. The cells are scored on a scale from 1 to 5:

pace in between them.

darker and have different shapes.

er cells have lost their ability to form glands. g other tissue.

re sheets of cancer cells throughout the tissue.

"Low-grade" tumor cells (those closest to 1) tend to look very similar to normal cells.

"High-grade" tumor cells (closest to 5) have mutated so much that they often barely resemble the normal cells.

These two grades are combined to create the Gleason Score, with the primary number reported first and the secondary number reported second (e.g. 3+3=6).

A Gleason score can theoretically range from 2 to 10; however, a score of 5 or lower is rare so a Gleason score 3+3=6 cancer is generally the lowest grade of prostate cancer diagnosed.

**GLEASON SCORE SUMMARY** 

<b>Gleason Score</b>	What does this mean?
2 - 6	The cancer is likely to grow and spread very slowly. If the cancer is small, many years may pass before it becomes a problem. Thus, you may never need cancer treatment.
7	The cancer is likely to grow and spread at a modest pace. If the cancer is small, several years may pass before it becomes a problem. To prevent problems, treatments is needed.
8 - 10	The cancer is likely to grow and spread fast. If the cancer is small, a few years may pass before the cancer becomes a problem. To prevent problems, treatment is needed now.

**The Gleason Score** The pathologist looking at the biopsy sample assigns one Gleason grade to the most similar pattern in your biopsy and a second Gleason grade to the second most similar pattern. The two grades added together determine your Gleason score (between 2 and 10).

Cancers with lower Gleason scores (2 - 4) tend to be less aggressive, while cancers with higher Gleason scores (7 - 10) tend to be more aggressive.

It's also important to know if any Gleason 5 is present, and most pathologists will report this. Having any Gleason 5 in your biopsy or prostate puts you at a higher risk of recurrence.

### **Understanding Your Pathology Report**

If you have been diagnosed with prostate cancer it is important to understand as much as you can about your condition. Because every prostate cancer is different, knowledge about the underlying biology of your tumor may help personalize your treatment plan. Your physician will perform several tests on your tumor tissue to provide specific information about your cancer. These tests will result in a pathology report. Your pathology report is one of the resources containing information about your tumor. This report will help guide your healthcare team in recommending an appropriate plan for you. Ask your doctor if there are additional tests you should consider ensuring you have the most complete understanding of your cancer.

**Gross Description:** Describes the color, weight and size of tissue as seen by the naked eye.

**PSA level:** Reflects the current level of prostate specific antigen (PSA) in your blood. In general, the higher the PSA, the higher the risk of cancer progression.

**Gleason Score:** A rating system that describes how the cancer cells look under the microscope. How the cells look is a very important predictor of how aggressive the cancer may be and very important for making management decisions.

**Tumor Cell Type:** The type of cancer cells in the tumor. The most common type (95% of prostate cancer) is an adenocarcinoma. Other types of prostate cancer, like small cell, neuroendocrine or signet cell, are rare.

**Number of cores:** Specifies how many tissue samples, or cores, were removed during the biopsy. It is typical to report how many cores had cancer, along with what percentage of each core included cancerous tissue.

**Location of cores:** Identifies from which area in the prostate an individual tissue core was taken: apex (part of the prostate furthest from the bladder), mid-zone (middle), or base (part of the prostate nearest the bladder).

**Lymphovascular/ Perineural Invasion:** Specifies whether or not there are tumor cells near blood vessels or nerves, respectively.

**Prostate Intraepithelial Neoplasia (PIN) or Atypical Small Acinar Proliferation (ASAP):** These findings indicate abnormal cells that are not clearly cancerous. Although they are not cancer, some doctors will recommend a repeat biopsy if either of these are found.

## STAGE VS. GRADE

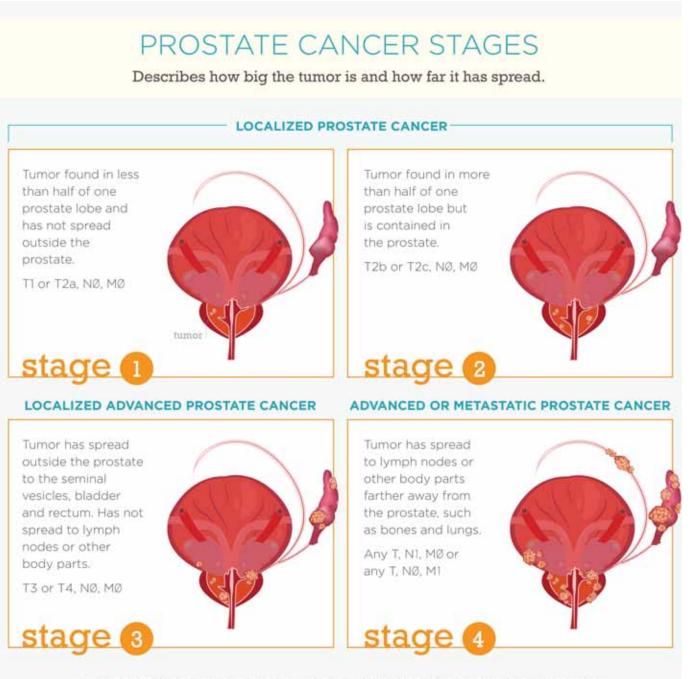
### **THE SIZE OF A TUMOR IS GROUPED INTO** 4 stages and defined by growth & spread.

The size (or stage) and grade of your tumor don't always predict its behavior over time. For example, a large tumor may be relatively slow to grow where as a small tumor might have aggressive properties. In some cases, using tumor DNA sequencing and biomarkers may be better predictors of growth over time. Consult with your health care provider to find out if these options might be right for you.

### THE GLEASON SCORE IS A GRADING system for how much prostate cancer cells retain their ability to form glands.

### **Understanding Cancer Stages**

Some pathologists have started reporting on tertiary Gleason patterns when a very small number of cancer cells that appear different from the primary and secondary patterns. Not all pathologists use this additional classification, but some experts believe it helps to inform management decisions.



Doctors rate the extent of prostate cancer with T, N, and M scores. The T score is a rating of size and extent of the primary tumor. The N score reflects if the cancer has spread to nearby lymph nodes. The M score reflects if the cancer has spread to distant sites.

#### The Stages Explained

**Stage 1** prostate cancer is limited to the prostate gland. The patient's Gleason score is six or lower, and their PSA level is nine or lower. Clinical Stage T1a-b: Cancer is diagnosed in prostate tissue removed during Transurethral Resection of the Prostate (TURP), a procedure for prostate enlargement. Clinical Stage T1c: Cancer is diagnosed based on a biopsy performed due to elevated PSA in the absence of any abnormality of the prostate on DRE. **Stage II** prostate cancer is still limited to the prostate gland, but the patient's Gleason score is a seven or higher and their PSA level is 10 or higher.

*Clinical Stage T2:* The cancer is detected on DRE but appears to be confined to the prostate.

T2a involves less than one half of one side of the prostate

T2b involves more than one half of one side of the prostate

T2c involves both sides of the prostate

**Stage III** prostate cancer has spread beyond the outer layer of the prostate (for instance, it may have spread to the seminal vesicles). The patient's PSA can be any level, and the Gleason score can be anywhere between two and 10.

Clinical Stage T3: The cancer is detected on DRE and appears to extend beyond the prostate, including into the seminal vesicles. T3a extends outside the prostate and T3b extends into the seminal vesicles.

**Stage IV** prostate cancer has spread to nearby lymph nodes, tissues or organs, or even distant parts of the body, such as the bones. Like stage III, stage IV prostate cancer can involve any PSA levels and Gleason scores that range between two and 10.

*Clinical Stage T4:* The cancer is detected on DRE and has invaded adjacent organs (e.g. bladder, rectum, pelvic wall).

### **TNM Scores**

The AJCC (American Joint Committee on Cancer) staging system is used to stage prostate cancer. In this system, the letters T, N, and M describe a different location of cancer growth. Your doctors will assign a score to each letter. These scores will be combined to assign a cancer stage.

TNM scores are very important for treatment planning.

**T** = **Tumor** The T score is a rating of the size and extent of the primary tumor. **T1 tumors** can't be felt or seen with imaging tests. They are found in tissue removed by biopsies or surgical treatment. For example, prostate cancer may be found in men who had an abnormal PSA level or who had an operation for urinary problems caused by an enlarged prostate. Prostate cancer discovered as a result of an operation for voiding problems is called an incidental finding.

- **Tla** means that incidental cancer was found in 5% or less of the removed tissue.
- **T1b** means that incidental cancer was found in more than 5% of the removed tissue.
- **Tlc** tumors are found by needle biopsy that was done for a high PSA level.

T2 tumors can be felt by your doctor during a DRE. They also may be seen with an imaging test. T2 scores are based on cancer growth within the lobes-the left and right halves of the prostate. T2 tumors haven't grown outside the prostate gland.

- **T2a** tumors haven't grown beyond half of one lobe.
- **T2b** tumors have grown beyond half of one lobe but not to the other lobe.

**T3 tumors** have grown outside the prostate. They have reached the connective tissue around the prostate, the seminal vesicles, or the neck of the bladder.

- **T3a** tumors have grown outside the prostate but not into the seminal vesicle(s).
- **T3b** tumors have grown outside the prostate and into the seminal vesicle(s).

T4 tumors are fixed to or have invaded other nearby tissues. Such tissues include the external sphincter, rectum, bladder, levator muscles, and pelvic wall.

**T4** tumors are fixed to or have grown into nearby tissues other than seminal vesicles. *(see illustration on page 18)* 

**N** = **Nodes** Lymph drains from around prostate cells into vessels that transport it to the bloodstream. As lymph travels, it passes through small, oval-shaped structures called lymph nodes. Lymph nodes remove germs from lymph. As shown in illustration, lymph nodes and vessels are found throughout the body.

The N category reflects if cancer cells have spread through lymph to nearby lymph nodes. Nearby lymph nodes include the hypogastric, obturator, internal and external iliac, and sacral lymph nodes. Most often, prostate cancer spreads to the external iliac, internal iliac, or obturator nodes. N scores for prostate cancer include:

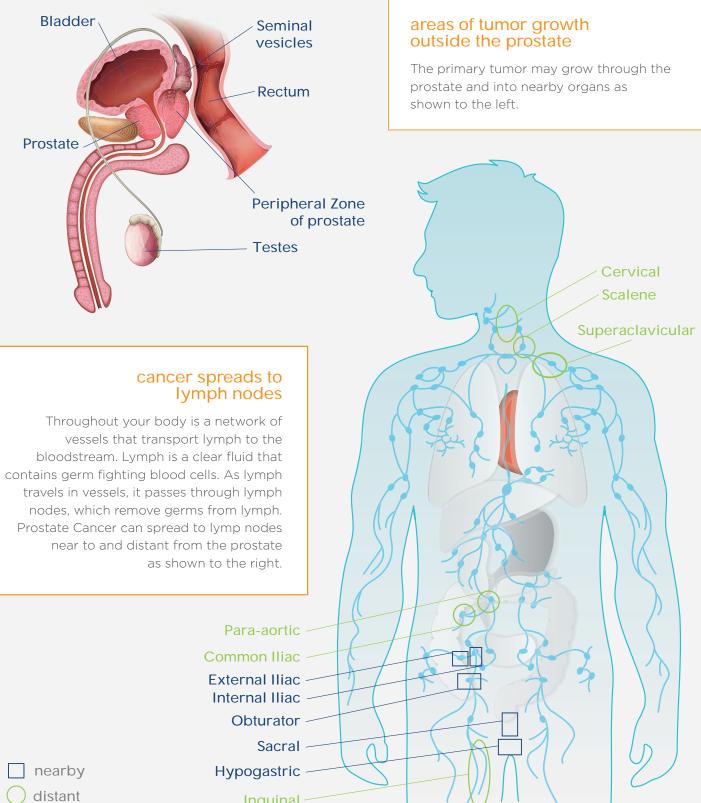
**T2c** tumors have grown into both lobes.

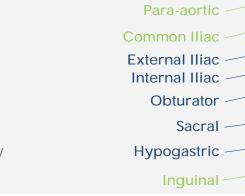
**NX** means it is unknown if there is cancer in lymph nodes.

**NØ** means that there is no cancer within the nearby lymph nodes.

**N1** means that the cancer has spread into the nearby lymph nodes.

## UNDERSTANDING HOW PROSTATE CANCER **SPREADS IN THE BODY**





### M = Metastasis

The M category tells you if the cancer has spread to distant sites. Para-aortic, common iliac, inguinal, supraclavicular, scalene, and cervical lymph nodes are distant from the prostate. Prostate cancer tends to metastasize to bone then the lungs and liver.

M scores for prostate cancer include:

- **MX** means it is unknown if cancer has spread to distant sites.
- **MØ** means that there is no growth to distant sites.

M1 means that the cancer has spread to distant sites.

- **Mla** is cancer that has spread to distant lymph nodes.
- **Mlb** is cancer that has spread to bone(s).
- **Mlc** is cancer that has spread to distant organs.



### Visit the resource center of the IPCF website for prevention tips, support groups, and more!

Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

### www.fightingprostatecancer.org/resources-1

There are many things that men can do to aid in the recovery and treatment of prostate cancer.

### TREATMENT APPROACH

### **Treat Or Not To Treat**

Men diagnosed with prostate cancer have many different options available, and there is no one-size-fits-all approach to prostate cancer. Prostate cancer grows at different rates in different individuals. Ideally, these very low-risk, low-risk, and even some select intermediate risk cancers may be managed with active surveillance - strict, regular monitoring of the cancer by your healthcare team with a decision to treat if/when the cancer shows more aggressive features.

Unfortunately, traditional clinical tests (biopsy, PSA, DRE) are not perfect predictors of how aggressive a given tumor will be. For some patients, doctors may recommend a biopsy-based genomic test that can be used in conjunction with traditional measures to help determine the true biological aggressiveness of a cancer.

Aggressive prostate cancers that have a high risk of growing and spreading should be treated in a timely manner. Your doctor may suggest treatment including surgery (radical prostatectomy), radiation therapy, cryosurgery, hormonal therapy, chemotherapy, and emerging new drugs or investigational agents. For each man, the potential benefits versus risks and side effects of treatment should be considered. Understanding your unique diagnosis will help you and your healthcare team determine which options will work best for you.

You should consult with your doctor regarding your screening or diagnosis and be empowered with your physician to make the move that is best for your specific case.

### Approach

Every man faces a wide array of options on how to treat their disease and the course of care they choose can vary greatly. You should learn as much as possible about the many treatment options available and, in conjunction with your physicians, decide what's best for you. Because men diagnosed with localized prostate cancer today may live for many years, any decision made now will probably reverberate for a long time. The suitability of prostate cancer treatment options must be based on several factors, including:

Stage of prostate cancer Current state of health and age Personal preferences Side effects of the different treatment options

For each man, the potential benefits versus risks and side effects of treatment should be considered. Your desire for a certain therapy should be based on risks, benefits, and your intuition. Consultation with all three types of prostate cancer specialists — a urologist, a radiation oncologist, and a medical oncologist — will give you the most comprehensive assessment of the available treatments and expected outcomes. Many hospitals and universities have multidisciplinary prostate cancer clinics that can provide this three-part consultation service.

In conclusion, do not be afraid to talk to your doctor about new emerging therapies. There are many exciting clinical trials ongoing around the country, involving novel agents that have great promise to help men with prostate cancer and many may be appropriate for your current condition.



### CAN FERTILITY **BE AFFECTED** BY PROSTATE CANCER?

Inflammation of the prostate gland, an englarged prostate, low testosterone, restricted blood flow in the pelvic region, as well as prostate cancer may affected healthy fertility.

For men who are hoping to father a child in the future, it is vital to have a discussion on fertility preservation and sperm cryopreservation with your physician before you undergo any prostate cancer treatment.

PSA, biopsy & DRE CAN HE assess the size of a tumor

### **Assembling Your Team**

Decisions about how to treat your prostate cancer can't be made in a vacuum. A new diagnosis can come with a lot of confusing information and feelings. Many aspects of this disease can affect the way you view yourself, the way you interact with others, and the way others interact with you. Yet at this chaotic time, you'll be asked to make some important decisions, based on your doctors' recommendations. To help you along the way, it's prudent to work with your network of family, friends, and practitioners to align expectations and seek support as appropriate.

**Doctors and Practitioners** Where possible, select a physician who specializes not just in cancer but in the nuances of your specific type of prostate cancer. How do you find such a doctor? If you are newly diagnosed, start by consulting your diagnosing doctor, that is, the one who found your prostate cancer. He or she may be an expert in the field, or they may refer you to one or more doctors who are.

### **DOCTORS AND PRACTITIONERS INVOLVED IN PROSTATE CANCER DIAGNOSIS AND TREATMENT**

**Urologists** specialize in problems affecting the urinary tract (kidney, bladder, prostate, urethra, penis and related organs).

**Urological Oncologists** perform surgeries for treating prostate and other urological cancers.

Genitourinary Oncologists perform surgeries for issues of the urinary and genital organs.

**Radiation Oncologists** specialize in the use of radiation therapy to treat cancer.

Medical Oncologists specialize in treating cancer with medical therapies, such as chemotherapy, hormone therapy, and targeted therapies.

Radiologists or Nuclear Medicine Physicians specialize in interpreting imaging scans that you may have and may also perform specialized biopsies or deliver radioactive medical therapies.

**Pathologists** specialize in interpreting the results from your biopsy or surgery to determine the type, extent, and grade of your cancer.

**Oncology Nurses** administer treatment and monitor your vitals as you progress through the disease.

Dietitians and Naturopathic Doctors counsel patients on nutrition issues related to cancer and treatment.

**Physical Therapists** create and execute rehabilitation programs to restore function and prevent disability following treatment. Occupational Therapists work with patients to help them develop, recover, and improve the skills needed for daily living and working. Genetic Counselors specialize in understanding and counseling you about inherited risks of cancer for you and your family. Social Workers, Therapists & Counselors help patients and their families cope with the emotional stress and the

major life changes that come with a cancer diagnosis.

### OTHER FACTORS TO CONSIDER WHEN SELECTING A DOCTOR:

- Are they covered by your health insurance?
- Are they affiliated with a university or research hospital?
- to you?

#### **REMEMBER:**

- Take your time
- Don't be afraid to shop around and get second or even third opinions
- *fightingprostatecancer.org* and those that your doctor recommends.
- and remain curious.

### Family

Your family wants to support you. Feelings of powerlessness are a common concern around a cancer diagnosis; your loved ones want-or even need-to do something to feel like they are helping. Normally, this may feel like a fantastic offer. But after a cancer diagnosis, you may feel confused about how much support to accept, request, or reject. Keeping open channels of communication is the key.

TIPS FOR SPOUSES, CAREGIVERS AND ADULT CHILDREN

- Agree on how you will make decisions
- Get ready for changes in routine
- Understand that there could be emotions from both sides around changes in ability

• Does their "bedside manner" align with your personality? Are they analytical? Compassionate? Do they seem interested in making you a partner in this process? Do they seem interested in what is important

• Be careful of random advice, e.g. "surgery is the best" or "radiation is the best" or "eat this herb and your cancer will be cured." For accurate information, use data on reputable websites like

• Once you have committed, trust is key, but continue to be your own advocate: ask questions, do research,

- Find out how treatments may affect moods, physical ability, and sexual function
- It is normal to experience loneliness and fear around a cancer diagnosis. Don't hesitate to seek out a support group for spouses and/or caretakers

#### TIPS FOR YOUNG CHILDREN

- Keep children informed, as age appropriate, and treat them as part of the team
- Be realistic but optimistic in your communications
- For older children, you might encourage them to join a support group. For younger children, consult your therapist for suggestions on how much information to share

For information on caregiving for a prostate cancer patient visit the downloads section of the resources center at www.fightingprostatecancer.org/resources-1 and download the Prostate Cancer Caregiver Guide.

### **Your Support Network**

Outside of your immediate family, there may be many close friends and colleagues who care deeply about you and have a strong desire to help. With friends and family who have volunteered their assistance, don't be shy about letting them know a few specific things that would be helpful to you. Examples might include rides to treatment, meals, caring for young children, or performing difficult chores during recovery. And when things feel overwhelming, don't be afraid to reach out for the support of family and friends. On the other hand, don't be shy about saying no to help you don't want, however generous. Visit the resources center at fightingprostatecancer.org for support groups, therapy ideas, awareness campaigns and much more.

Many friends and family choose to become active in the cancer community in order to diminish the common feeling of powerlessness that can comes with a loved one's cancer diagnosis. For more info on getting involved, visit the resources center at fightingprostatecancer.org

### Self Care Build A Plan — For Yourself

Sadness, fear, sleeplessness, and anger are all normal early emotions around a cancer diagnosis. Coping with these emotions isn't something you should take lightly. Seeking professional help, either from an online community, clergy, a church group, a cancer support group, or a private mental health professional isn't a sign of weakness. Taking care of your mental health is akin to the kind of psychological training that a quarterback goes through to make sure he can keep his head in the game: it's vital.

Over the course of your cancer journey, it's important to pay close attention to your overall health. You may have to modify your daily habits. Many people living with cancer may experience both nutritional and emotional difficulties during their cancer treatment.

There are experts who can offer you nutrition advice. Registered dietitians are food and nutrition experts who have studied how diet and dietary supplements affect your health. Some even have additional training in oncology nutrition.

Cancer can certainly make it difficult to feel engaged or connected to the moment. For patients who have been diagnosed with advanced cancer or facing end-of-life issues, their mind can be so full of worry and stress that they struggle to be present and aware of the time they have right now. Fortunately, there have been many advances and patients are finding alternative ways to cope with both the physical and emotional challenges that come with this disease.

### SELF CARE AND HEALTH MANAGEMENT STRATEGIES





If you choose to take control of your own health and wellness plan, here are some health management strategies and ideas to help you practice whole body care and mindfulness.

Research has shown that physical activity is very important, especially with cancer. It can improve patient function physically as well as their quality of life. The most important thing for your cancer treatment and exercise recovery is to listen to the body. If you are feeling tired, sore or notice decreased performance, you may need more recovery time or a break from exercise altogether. Pay attention, in most cases, the body will communicate what it needs, when it needs it. Listen and be kind to the body, and the body will be kind to you.

Always remember, too much rest can lead to loss of body function, muscle weakness, and reduced range of motion. So today, many cancer care teams are urging their patients to be as physically active as possible during cancer treatment. Many patients and caregivers are learning about the advantages of being physically active after treatment, too.

### **Processing Your Diagnosis**

The final decision on treatment is yours and may be informed by a variety of psychological as well as clinical factors. Sometimes this decision process can be empowering, and sometimes it can be bewildering. For example, although the first instinct may be to choose a therapy from the first provider you see who promises to eradicate the disease, you should take your time to investigate your options. Depending on the features of your cancer, your age, overall health, and personal family circumstances, active surveillance may be the right choice for you.

Side effects of each treatment are also important to consider, and only you can know what potential outcomes are acceptable to you. Regardless of which treatment you choose, it's important to observe recommended diet and lifestyle modifications from the moment you are diagnosed. In the end, after all your research into different treatment types, side effects, different doctors, and different hospitals, the decision is going to come down to you. If there was one right answer that fit every man, we would tell you!

However, the decision is unique to you and it may not be right for your brother, your friend, or any of the twenty other people you consulted, but you need to decide what is the best choice for you to get started on the road to a better health. Some people find the decision process liberating; others find it beyond their individual ability. Remember that it is okay to feel overwhelmed at first. Use this guide to begin to understand your options, but please rely on professionals, friends, and family to help you navigate your final treatment plan.

### **Tear Sheet - Questions To Ask**

Thanks to recent advances in treatment, men who are diagnosed with prostate cancer today have many options available to them. It's important to understand the basics of prostate cancer and identify with your medical team what treatment options are right for you. Remember, you want to be a partner in your own care. The more educated and proactive you are, the better. On the next page are a few questions to help guide conversations with your treatment providers. Be sure to add any additional questions you have.

For additional questions on an initial prostate cancer diagnosis that hasn't progressed to advanced stages visit the downloads section of the resources center at www.fightingprostatecancer.org/resources-1 and download the Prostate Cancer Guide.

### **TEAR SHEET:** QUESTIONS TO ASK AFTER INITIAL ADVANCED PROSTATE CANCER DIAGNOSIS

- stage and aggressiveness of my cancer?
- What is my prostate cancer grade? What does this mean in terms of our approach to my treatment?
- How many men with prostate cancer do you treat (with surgery, radiation, etc) per year?
- that i've been diagnosed with prostate cancer? Can you refer me to a dietitian?
- Has my cancer spread beyond the prostate? Can it be cured?
- How long should I try a treatment type before we know whether it works?
- What are the benefits of the type of therapy you are recommending? What are the drawbacks/side effects of this type of therapy?
- make? What about exercise?
- effects? What can I do to protect my bones?
- What kind of follow-up can I expect after treatment?
- Can you refer me to another expert for a second (or third) opinion?
- measures before I undergo any treatments?
- problems?
- 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 put me in touch with a support group?

What is my psa level? If multiple values over time have been collected, how fast has it risen, and what does this mean for me? What does "advanced cancer" mean for me?

Do I need immediate therapy? What is my risk of progression over time without therapy?

Are there additional tests that we can do to gain the most complete understanding of the

Which treatment do you recommend for me and why? What other treatment(s) might be appropriate and why? Would a clinical trial be an option for me?

How can I help my overall health? What should I do to keep my body and mind healthy now

What can I do to improve the success of my therapy? Are there dietary changes I need to

What can I do to manage my symptoms? What can I do to manage or prevent treatment side

Are the risks different with different treatments? If I speak to other specialists for second opinions before making a final decision on my plan of action, how do we coordinate it?

What is the effect of the treatments on my fertility? Should I consider sperm-banking or other

Will I have problems with incontinence or impotence? Will I have other urinary or rectal

### TREATMENT OPTIONS AT A GLANCE

Understanding the treatment options and consulting your healthcare team will help you determine which option(s) will work best for your specific situation. There are also always new emerging therapies being researched and developed.



no symptoms and slow growing

Destroys cancer cells by delivering

freezing temperatures of minus 40°

to the prostate. It is minimally invasive.

## 4. TREATMENT OPTIONS – Choosing & Monitoring your Treatment

Advanced prostate cancer is not "curable," but there are many ways to treat it. Treatment can help slow advanced prostate cancer progression. The goal of advanced prostate cancer treatment is to shrink or control tumor growth and control symptoms.

Knowing what a treatment is will help you understand your treatment options. Not every man with prostate cancer will receive every treatment listed. Before any treatment, talk with your doctor about sperm-banking if you plan to have children.

There are many treatment choices for advanced prostate cancer. Which treatment to use, and when, will depend on discussions with your doctor. There are many benefits and risks to each type of treatment or therapy, so ask questions of your doctor so you understand what is best for you.

Choosing the best treatment for localized or locally advanced prostate cancer is generally based on age, the stage and grade of the cancer, the patient's general health, and an evaluation of the risks and benefits of each therapy option.

### **Risk Groups**

Health care providers think about localized or locally advanced prostate cancer is in terms of "risk groups," which are assigned before the patient undergoes any treatment. There are 3 general risk groups based on the PSA, DRE, and biopsy, which can further be subdivided to better personalize treatment for each patient.

**1. Low risk:** Tumor confined to the prostate, the PSA is <10 and grade group 1 (Gleason 6). There is also a subset of extremely "slow-growing" tumors called "very low risk" in which fewer than 3 biopsy tissue samples contain cancer cells and the cancer is not detectable by DRE.

**2. Intermediate risk:** Tumor is confined to the prostate, the PSA is between 10 and 20, or grade group 2 or 3 (Gleason 7). This category is often divided into a "favorable" and "unfavorable" intermediate risk.

**3. High risk:** Tumor extends outside the prostate, the PSA >20, or grade group 4 or 5 (Gleason 8 to 10). There is also a subset of very aggressive tumors is called "very high risk" in which the tumor has extended into the seminal vesicles (T3b) or the rectum or bladder (T4), or there are multiple biopsy samples with high grade cancer.

These risk groups are not perfect indicators of your risk for developing recurrent, aggressive prostate cancer. Currently, there are extensive, ongoing efforts to develop tests that can aid physicians in more accurately telling the difference between cancers that will become fatal from those that will sit in the prostate without spreading.

The treatment options for each risk group are very different and you should ask your doctor which risk group you belong to so you can better understand the most appropriate next steps.

therapy advantaged or metastatic stages

Stimulates the immune system to fight the cancer, may be used alone or in conjunction with other treatments.

### TREATMENT OPTIONS

### **Active Surveillance**

Active Surveillance is based on the concept that low-risk prostate cancer is unlikely to harm you or decrease your life expectancy. Over 30% of men have prostate cancers that are so slow growing, making Active Surveillance a better choice than immediate local treatment with surgery or radiation. Active Surveillance is not "no treatment," but rather a strategy to treat you only if and when your cancer warrants treatment (some think of it as deferred treatment only if you need it).

Men with low-risk prostate cancer who have been on Active Surveillance for 10 to 15 years after diagnosis have remarkably low rates of their disease spreading or dying of prostate cancer. In fact, a Johns Hopkins study of men on Active Surveillance found that, 15 years later, less than 1% of men developed metastatic disease. The key to these successful numbers is making sure you are monitored regularly for signs of progression. A PSA blood test and digital rectal exam (DRE) are usually done once or twice per year by your urologist, with a repeat biopsy of the prostate every 1 to 5 years. If there is evidence that the cancer is progressing, treatment may be warranted.

**Who Should Choose Active Surveillance?** Some of the characteristics that might qualify you for Active Surveillance include grade group 1, Gleason 6, PSA <10, cancer that is confined to the prostate and/ or cancer that is very low volume when biopsied. The ideal candidate for Active Surveillance has low-risk prostate cancer.

The right age for Active Surveillance is a difficult question, as clearly younger men will live longer with their cancers, and thus have a higher likelihood that their cancer could progress. However, younger men who appear to have less aggressive cancers may be able to stay on Active Surveillance longer.

Active Surveillance may also be more appropriate for men who are currently battling other serious disorders or diseases — such as significant heart disease, longstanding high blood pressure, or poorly controlled diabetes — the patient and his doctors might feel that performing invasive tests or treatment would cause more harm than benefit, except to help manage any symptoms that occur due to advanced disease.

As with any treatment for prostate cancer, shared decision-making with a physician is necessary. Some physicians also administer commercial genetic tests—such as Decipher, Oncotype Dx<sup>®</sup> Prostate, and Prolaris<sup>®</sup>— that may be helpful in determining if you are a good candidate for Active Surveillance.

### **Robotic-Assisted Radical Prostatectomy**

Highly advanced technology has led to the development of a revolutionary new form of prostate surgery, the roboticassisted radical prostatectomy. Prostatectomy is the most common prostate cancer treatment for early-stage localized cancer in the United States today. Sometimes, physicians choose to use other therapies in conjunction with surgery.

Robotic-assisted radical prostatectomy surgery has become very popular over the past 10 years due to the smaller incisions and a shorter post-operative in-hospital-recovery period (typically 1-2 days). Experienced surgeons transfer their skills into a laparoscopic environment that employs highly precise instruments and magnified vision. This minimally-invasive procedure is quickly gaining popularity as the most preferred cancer treatment for surgical removal of the prostate.

Robotic-assisted prostate surgery is designed to promote a quicker recovery and an overall optimal patient experience and has consistently demonstrated superior outcomes in cancer control, incontinence and impotence.

**What to Expect** Robotic Radical Prostatectomy requires small incisions to be made in the abdomen by the surgeon. With a robotic interface, the surgeon then controls the robot's arms, which in turn control the cameras and instruments.

Although robotic surgery creates much smaller incisions than open surgery, there is still a large surgery occurring inside the body. For this reason, there is an important healing process that must occur post-operatively. After the usual 1 to 2-night stay in the hospital, patients typically go home with some form of catheter to help drain urine for 7-10 days. In the initial weeks to months after surgery, it is expected and common to have incontinence or leakage of urine and you will need to wear diapers or pads, but this generally improves significantly over the first year following surgery.

During the first 2 months after surgery, exercise, golf, and most physical activities are prohibited while the abdominal muscles heal from the incisions.

**The Importance of Surgical Skill** Prostatectomy, like many surgical procedures, is very delicate work, and the difference between a good surgeon and a great surgeon can affect outcomes. As many studies have shown, surgeons who are at the top percentiles of prostatectomies performed have the best outcomes.

When choosing a surgeon, at a minimum, ensure that he or she is someone in whom you have confidence and trust, and someone who has enough experience to not only perform the operation, but also to make an informed clinical judgment if necessary.

**Nerve-Sparing Surgical Techniques** In a nerve-sparing prostatectomy, the surgeon cuts to the very edges of the prostate, taking care to spare the erectile nerves that run alongside the prostate. Sometimes the nerves cannot be spared because cancer extends beyond the prostate requiring a more extensive resection.

### Cryosurgery

Cryosurgery (also called cryotherapy) is the use of extreme cold to destroy cancer cells. It may be used in cases of recurrent prostate cancer if the cancer has not spread beyond the prostate.

Cryotherapy is a minimally invasive prostate cancer treatment that does not involve open surgery or radiation to destroy prostate cancer. The procedure destroys cancerous cells by delivering freezing temperatures of minus 40° Celsius to the prostate.

This procedure involves applying cold argon gas via a thin needle into the prostate tumor, freezing the prostate tumors to kill the cancer cells. Cryosurgery is FDA-approved but not widely used at this time. It is also sometimes used as salvage therapy (when all other treatment options have failed) for patients who have residual disease that is still confined to the prostate.

The use of hollow probes introduces cold gases into the affected area of the prostate, destroying cancer cells. A physician who has thoroughly evaluated a patient's case may recommend this procedure instead of a radical prostatectomy, in which the entire prostate (and any surrounding tissues that are affected) is removed.

This lethal freeze immediately destroys cancerous cells by: Causing membrane damage Cutting off the oxygen supply

### **Other Surgery Options**

In some cases of advanced or recurrent prostate cancer, surgeons may remove the entire prostate gland in a surgery known as "salvage" prostatectomy. They usually do not perform the nerve-sparing form of prostatectomy. Often, surgeons will remove the pelvic lymph nodes at the same time.

To reduce testosterone levels in the body, doctors may sometimes recommend removing the testicles, a surgery called orchiectomy. After this surgery, some men choose to get prosthetics (artificial body parts) that resemble the shape of testicles.

Doctors may also remove part of the prostate gland with one of two procedures, either a transurethral resection of the prostate (TURP) or a transurethral incision of the prostate (TUIP). This relieves blockage caused by the prostate tumor, so urine can flow normally. This is a palliative measure, which means it is done to increase the patient's comfort level, not to treat the prostate cancer itself.

### **Primary Hormone Therapy (also known as Endocrine Therapy)**

Hormone therapy (also called endocrine therapy, hormone treatment, or androgen-derivation therapy) slows or stops the growth of hormone-sensitive tumors by blocking the body's ability to produce hormones or by interfering with effects of hormones on cancer cells.

Endocrine therapy is the main treatment for advanced prostate cancer. It is the first line of treatment for metastatic prostate cancer. However, there are also some situations in which surgery is done to decrease the testosterone level immediately, rather than waiting for medications to take effect.

Drugs work as well as prostate cancer surgery to reduce the level of hormones in the body. Male hormones, specifically testosterone, fuel the growth of prostate cancer. By reducing the amount and activity of testosterone the growth of advanced prostate cancer is slowed. In many patients, endocrine therapy provides temporary relief of the symptoms that accompany advanced prostate cancer. Endocrine therapy may reduce tumor size and levels of prostate specific antigen (PSA) in most men. PSA is a substance produced by the prostate gland that, when present in excess amounts, signals the presence of prostate cancer.

Hormone therapy, also known as androgen-deprivation therapy or ADT, is designed to stop testosterone from being released or to prevent it from acting on the prostate cells. Although hormone therapy plays an important role in men with advancing prostate cancer, it is increasingly being used before, during, or after local treatment as well.

Most commonly given with radiation therapy, hormone therapy usually consists of a shot that lowers your testosterone, and is given every 1 to 6 months, or sometimes as a daily pill that blocks testosterone from reaching the cancer cells. Prostate cancer cells are like other living organisms - they need fuel to grow and survive. Because the hormone testosterone serves as the main fuel for prostate cancer cell growth, it's a common target for therapeutic intervention in men with the disease.

Most cells in prostate cancer tumors respond to the removal of testosterone. But some cells grow independent of testosterone and remain unaffected by hormone therapy. As these hormone-independent cells continue to grow unchecked, hormone therapies have less and less of an effect on the growth of the tumor over time.

For this reason, hormone therapy is not a perfect strategy in the fight against prostate cancer, and it does not cure the disease. It also carries some unwanted toxicities. But it remains an important step in the process of managing advancing disease, and it will likely be a part of every man's therapeutic regimen at some point during his fight against recurrent or advanced prostate cancer.

However, hormone therapy is not without side effects. Some of the more serious side effects include loss of sex drive, impotence, weakened bones (osteoporosis), and heart problems.

Eventually, most patients with advanced prostate cancer stop responding to hormone therapy. Doctors call this castrateresistant prostate cancer (see section CRPC on page 10).

Androgen deprivation therapy — Treatments that decrease the body's levels of androgens can also decrease the size of the cancer in the prostate as well as other areas (metastases). These treatments are called "androgen deprivation therapy" or "ADT."

ADT is usually recommended as the initial treatment for males with metastatic prostate cancer. ADT may be combined with another drug (see 'Combined approaches' on page 63). The recommended treatment approach depends on several factors, including how quickly the disease is expected to progress and the number and location of metastases.

ADT can be done by taking medicines that interfere with androgens or by having surgery to remove the testicles (also known as castration). In many countries, including the United States, the use of medicines is usually preferred over surgery. The medicines used in this context have the same effect as surgery, as they are a form of "chemical castration" (meaning that they stop the production of androgens even though the testicles are not removed).

### EXAMPLES OF THE MEDICINES USED FOR ADT INCLUDE THE FOLLOWING:

- (see below).
- progressing before treatment becomes effective.

• **GnRH agonists** — Gonadotropin-releasing hormone (GnRH) agonists are medicines that temporarily "turn off" the testicles' production of male hormones (androgens). This starves the cancer cells, causing the prostate to shrink. GnRH agonists are given as a shot every one to six months or as a depot that lasts 12 months, and they include leuprolide (sample brand name: Lupron) and goserelin (brand name: Zoladex). Sometimes, at the beginning of treatment, there may be a temporary surge in the body's levels of androgens before they begin to decline (called a "flare"). Some males may experience a worsening of symptoms (eg, bone pain) because of a temporary growth of the tumor during this brief period. One way that doctors can try to avoid this is to add a second medicine, called an "antiandrogen," to the GnRH agonist, at least initially

• **GnRH** antagonist — Degarelix (brand name: Firmagon) is a GnRH antagonist that temporarily "turns off" the testicles' production of male hormones (androgens). This medicine is more rapidly acting than a GnRH agonist and may be useful for situations where there is major concern about the disease temporarily

- **Relugolix (brand name: Orgovyx)** another GnRH antagonist that is available in pill form and may be more convenient than shots of either a GnRH agonist or antagonist.
- Combined androgen blockade Some doctors recommend a second medicine, called an "antiandrogen," in addition to the GnRH agonist for at least a short period of time. Examples of antiandrogens include flutamide (sample brand name: Eulexin) and bicalutamide (brand name: Casodex). These medicines are especially helpful when GnRH agonists are being started. That's because GnRH agonists boost androgen production for a short time at the beginning, before they shut down its production. This boost can temporarily cause the cancer to flare (get worse). The antiandrogen blocks that flare.

**Timing of ADT** — Whether to start ADT immediately or delay it depends on how far the disease has spread and the risk of further progression. In people considered high risk for progression early ADT may be recommended, while in other cases (for example, if the person does not have symptoms or evidence of metastasis) delaying ADT may be an option.

In some cases, "intermittent" (rather than continuous) ADT may be offered. This involves taking breaks by being off medication for a little while and then restarting the treatment. This allows time for side effects to ease, which can improve quality of life (see 'Side effects of ADT' below.) Intermittent ADT is typically not recommended for people with metastatic prostate cancer unless the person places a higher value on improving quality of life than maximizing overall survival. It may, however, be an option for some people who have had local therapy to treat early cancer (e.g., surgical removal of the prostate) and have had a rise in their PSA level but no evidence of metastatic disease.

Your urologist can talk to you in detail about your options and the best approach for your situation.

**Side effects of ADT** — The side effects of ADT are related to the lowered levels of male hormones and include the following:

- Decreased libido (sex drive) and difficulties with erection (erectile dysfunction)
- Mood swings
- Erectile dysfunction, the inability to have or keep a strong enough erection for sex
- Hot flashes or sudden spread of warmth to the face, neck and upper body, heavy sweating
- Weight gain of 10 to 15 pounds. Dieting, eating fewer processed foods and exercising may reduce weight gain
- Depression to include feeling loss of hope, loss of interest in enjoyable activities, not being able to concentrate or changes in appetite and sleeping
- Fatigue (feeling tired) that doesn't go away with rest or sleep
- Anemia (low red blood cell count) due to less oxygen getting to tissues and organs, causing tiredness or weakness
- Weak bones (loss of bone mineral density) or bones getting thinner, brittle and easier to break
- Memory loss
- High cholesterol, especially LDL ("bad") cholesterol

- Breast nipple tenderness or increased breast tissue growth
- Enlargement of the breasts (called gynecomastia)
- Loss of muscle causing weakness or low strength and/or an increase in body fat
- Thinning and weakening of the bones (called "osteoporosis"), which can increase the risk of bone fractures an increased risk of developing type 2 diabetes
- May increase cardiovascular risk A potential small increased risk of developing or worsening coronary heart disease, which can lead to heart attack (although this is controversial)

Many of these side effects are serious, and they might seem frightening. However, not all males have these side effects. In addition, it is important to balance the risk of side effects with the risk of not using ADT, which could allow your cancer to grow or spread. In most men, the risk of the cancer growing or spreading outweighs the possible risk of side effects. In addition, there are ways to prevent or treat many of these side effects.

**Options at the time of disease progression** — Most males with advanced prostate cancer initially respond well to treatment that includes ADT but then their prostate cancer comes back, often within a few years. At this point, the cancer may be termed "castration resistant" or "castrate resistant," meaning that ADT is no longer effective. When this occurs, your doctor will work with you to choose another ("secondary") form of treatment to try.

### **Radiation Therapy**

Radiation uses high-energy beams to kill tumors and may be given once or over several visits. Radiation involves the killing of cancer cells and surrounding tissue with ionizing radiation or photons. Radiation damages the cancer cells' DNA, the genetic material of the cancer cell, so it can't survive or grow and spread, and subsequently the cancer cells die. Radiation therapy, like surgery, is very effective in killing localized or locally-advanced prostate cancer and has the same cure rate as surgery. Some forms of radiation therapy can also be used in men with advanced or recurrent prostate cancer.

Regardless of the form of external radiation therapy, it is non-invasive and is done on an outpatient basis. Because it is non-invasive (no cutting) there is no down time or healing time as there is with surgery. You can

### RADIATION TRFATMENT SIDE EFFECTS

The below can be some of the radiation side effects



be physically active every day of treatment and the months following. It is common though to have increased frequency of urination or bowel movements during the weeks of treatment, and 4-6 weeks after treatment is done, these symptoms generally improve over the months following radiation therapy.

Many studies have shown that while surgery results in a more immediate loss of erectile function followed by a period of recovery, radiation therapy results in a slower loss of erectile function over time in men who have good erectile function before treatment. By the end of five years, the risks of erectile dysfunction appear to be similar in men who have chosen radiation or surgery.

**External Beam Radiation Therapy** This is the most common type of radiation therapy. CT scans and MRIs are used to map out the location of the tumor cells, and X-rays are targeted to those areas. With 3-D conformal radiotherapy, a computerized program maps out the exact location of the prostate tumors so that the highest dose of radiation can reach the cancer cells within the gland. Regardless of the form of external radiation therapy, treatment courses usually run five days a week for about seven or eight weeks and are typically done on an outpatient basis.

**Proton Beam Therapy** Protons are like x-rays or photons, in that they are both essentially radiation and they kill the cancer similarly. There are mixed reports as to whether there are increased or decreased side effects with the proton beam. Protons for prostate cancer should be viewed as an area of active research, and you should talk to your doctor about them. Insurance companies often do not cover proton beam therapy and it is the most expensive form of treatment for prostate cancer.

The advantage of using protons over other external beam sources is precision. Protons of energetic particles can hit a targeted prostate cancer tumor without affecting surrounding tissue. This direct attack on cancerous cells ultimately causes their death, as the cells are particularly vulnerable to attack due to their rapid division.

Proton treatment is suitable for treating localized, isolated, solid tumors before they spread to other tissues and the rest of the body. However, to date, proton beam therapy has never been compared directly to standard IMRT techniques, so we do not truly know if this offers an advantage over standard approaches.

**Brachytherapy** is internal radiation therapy, rather than external radiation therapy. It involved placing different types of radiation therapy inside the prostate the emit radiation a very short distance. Tiny metal pellets (also referred to as seed implants) containing radioactive iodine or palladium are inserted into the prostate via needles that enter through the skin behind the testicles. As with 3-D conformal radiation therapy, maps are used to ensure that the seeds are placed in the proper locations. Over the course of several months, the seeds give off radiation to the immediate surrounding area, killing the prostate cancer cells. By the end of the year, the radioactive material degrades, and the seeds that remain are harmless.

Radioactive seeds (LDR or low dose rate) or catheters (HDR or high dose rate) are placed directly into the prostate while you are asleep under anesthesia. It is usually done in 1 to 4 treatment sessions depending on the method used. The seeds are permanently placed into your prostate, while the catheters are only temporarily placed inside the prostate and then removed after treatment is done.

Compared with external radiation therapy, brachytherapy is less commonly used, but it's rapidly gaining ground, primarily because it doesn't require daily visits to the treatment center. Side effects can include erectile dysfunction, urinary frequency and obstruction, and, rarely, rectal injury. Patients with large prostates or those patients with a lot of urinary problems are usually poor candidates for brachytherapy.

Some radiation techniques focus on saving nearby healthy tissue. Computers and software allow better planning and targeting of radiation doses. Now it is possible to target the radiation to pinpoint where it is needed.

**Stereotactic body radiation therapy (SBRT)** — This precision treatment allows radiation to be delivered in just five quick doses. The technique uses the latest technologies to deliver these higher doses in a safe and effective way - with fewer side effects. The entire course of therapy can be completed in about two weeks, making this the quickest radiation therapy option for prostate cancer.

**Proton therapy** — Using protons to deliver radiation, this treatment works by damaging the DNA of cancer cells, which causes the cells to die and the tumor to shrink. The nature of protons allows them to be manipulated to release most of their energy within a tumor with little to no dose in the surrounding healthy tissue. The result is a more precise radiation treatment with fewer side effects – which is particularly important for patients with certain types of cancer.

**SpaceOAR™** — If your treatment plan includes radiation therapy, SpaceOAR — a small hydrogel spacer made mostly from water, that temporarily moves the rectal wall further away from the prostate to protect against unintentional damage to the rectal wall during radiation treatment. This innovative, protective gel barrier is applied during a minimally invasive procedure and is eventually naturally absorbed by your body.

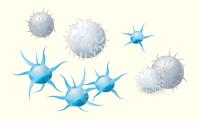
#### SIDE EFFECTS OF RADIATION:

- Dry mouth
- Mouth and gum sores
- Difficulty swallowing, sore throat
- Stiffness in the jaw
- Hair loss
- Lymphedema
- Tooth decay
- Skin changes
- Fatigue
- Shortness of breath
- Breast or nipple soreness
- Shoulder stiffness
- and 6 months after radiation therapy ends.
- Radiation fibrosis, which causes permanent lung scarring from untreated radiation pneumonitis. Your radiation oncologist will know how to lower the risk of fibrosis.
- · Loss of appetite, nausea, and vomiting
- Bowel cramping, loose stool, diarrhea, or rectal bleeding
- Incontinence and bladder irritation

• Cough, fever, and fullness of the chest, known as radiation pneumonitis. This happens between 2 weeks

### **CHEMOTHERAPY** SIDE EFFECTS

The below can be some of the chemotherapy side effects



DECREASE IN **PLATELETS & WHITE BLOOD CELLS** 



### CONSTIPATION. DIARRHEA, OR RENAL FAILURE



- Sexual problems, which includes physical and emotional changes that affect your sex life and intimacy. Problems can include erectile dysfunction, which is the inability to get or maintain an erection of the penis.
- Fertility problems

Many of these side effects are serious, and they might seem frightening. However, not all males have these side effects. It is also important to balance the risk of side effects with the risk of not using the treatment, which could allow your cancer to grow or spread. In most men, the risk of the cancer growing or spreading outweighs the possible risk of side effects. In addition, there are ways to prevent or treat many of these side effects.

### Chemotherapy

The term "chemotherapy" refers to any type of therapy that uses chemicals to kill or halt the growth of cancer cells. The drugs work in a variety of ways but are all based on the same simple principle: stop the cells from dividing and you stop the growth and spread of the tumor.

Until recently, chemotherapy was used only to relieve symptoms associated with very advanced or metastatic disease. With the publication of two studies in 2004 showing that the use of docetaxel (Taxotere) can prolong the lives of men with prostate cancer that no longer responds to hormone therapy, more and more doctors are recognizing the potential benefits of chemotherapy for the men they treat with advanced prostate cancer.

Chemotherapy is now often recommended in combination with ADT as the initial treatment for males whose cancer has already spread outside of the prostate, typically to the bones or other organs. It may also be offered to males with advanced prostate cancer who have stopped responding to their initial therapy, including all forms of hormone therapy. For more in-depth information on Combined Therapies, please reference the section later on page 63.

Building on these successes, there are now dozens of clinical trials studying various combinations of chemotherapy drugs, some using new mixes of older drugs and some using newer drugs. Some trials are looking to find a chemotherapy regimen that's more tolerable or more effective than docetaxel in men with metastatic disease, others are looking to find a chemotherapy regimen that can delay the onset of metastases, and still others are seeking to improve upon the results with docetaxel by adding other novel agents and testing the combination. Currently, the standard of care for men with metastatic prostate cancer and is progressing despite low levels of testosterone is docetaxel every 3 weeks, given with prednisone. If the cancer has spread to the bones, giving zoledronic acid with docetaxel is recommended.

In addition, several agents are approved or widely available for use in prostate cancer, including estramustine and mitoxantrone. Estramustine (Emcyt) is an oral medication with hormonal and chemotherapeutic properties that has anticancer activity and can be safely combined with other chemotherapies. Mitoxantrone (Novatrone) is a chemotherapy agent given intravenously every three weeks and, from earlier studies, is known to delay and reduce pain from prostate cancer metastasis. It remains an effective weapon against prostate cancer.

The most used chemotherapy agent is docetaxel (brand names: Docefrez, Taxotere), which is given into the vein (intravenously - IV). Studies have shown that adding docetaxel to ADT, when treatment is first started, improves survival over ADT alone.

**Docetaxel**, when used with or without prednisone, was the first chemotherapy drug proven to help patients live longer with advanced prostate cancer. The average survival was improved by about 2.5 months when compared to mitoxantrone with or without prednisone. Docetaxel has the best results when given every three weeks as compared to weekly dosing.

**Cabazitaxel** (**Jevtana**) is another chemotherapy drug, used in combination with the steroid prednisone, to treat men with prostate cancer. Cabazitaxel (Jevtana) is used in men with advanced prostate cancer that has progressed during, or after, treatment with docetaxel (Taxotere).

The safety of cabazitaxel (Jevtana) and its effectiveness were established in a single, 755-patient study. All study participants had previously received docetaxel (Taxotere). The study was designed to measure overall survival (the length of time before death) in men who received cabazitaxel (Jevtana) in combination with prednisone as compared to those who received the chemotherapy drug mitoxantrone in combination with prednisone. The median overall survival for patients receiving the cabazitaxel (Jevtana) was 15.1 months compared with 12.7 months for those who received the mitoxantrone regimen.

### SIDE EFFECTS IN THOSE TREATED WITH CABAZITAXEL (JEVTANA) INCLUDED:

- significant decrease in infection-fighting white blood cells (neutropenia)
- anemia
- low level of platelets in the blood (thrombocytopenia)
- diarrhea
- fatigue
- nausea and vomiting
- constipation
- weakness
- renal failure

Chemotherapy is not given every day; instead, it is given in cycles. A cycle of chemotherapy (which is typically 21 days) refers to the time it takes to give the treatment and then allow the body to recover from the side effects of the

medicines. Most of the studies demonstrating benefit from adding docetaxel to ADT have used six cycles of treatment for a total of 18 weeks.

SIDE EFFECTS OF CHEMOTHERAPY CAN INCLUDE THE FOLLOWING:

- temporary hair loss
- nausea and vomiting
- a decrease in the number of blood cells that fight infection (white blood cells), which increases the risk of developing an infection
- bone Marrow Suppression (the decline or halt of blood cell formation)
- patients may also experience neuropathy (nerve damage causing tingling, numbness, or pain in the fingers or toes) and fluid retention

### **Bisphosphonate Therapy (also known as Bone Targeted Therapy)**

The bone cells in our bodies are constantly being slowly removed and replaced with new bone cells. This happens throughout our entire life. Osteoclasts are cells in our bodies that remove old bone and the osteoblast cells replace it with new bone.

Cancers that spread to the bones damage the bones as they grow. The cancer cells that have spread into the bones also release proteins that interfere with the normal bone shaping process. These proteins are cytokines and growth factors. The proteins stimulate the cells that break down bone (osteoclasts) and make them overactive, so bone is destroyed faster than it's rebuilt.

Bisphosphonates work by stopping the removal of old bone osteoclast activity. As we age and in certain diseases, the bone is being removed or damaged faster than your body can replace it. This leaves the bone thin/weak and much more likely to fracture with a significant impact or fall. Bisphosphonate medications damage/kill the osteoclasts and stop removal of old bone to try and preserve your bone strength. They can also help to treat some types of cancer that cause bone damage.

*The family of Bisphosphonates includes:* 

Oral: Alendronate (Fosamax), Risedronate (Actonel), and Ibandronate (Boniva). IV drip: Pamidronate, and Zoledronic acid (Reclast/Zometa).

These medications are given as an infusion every 3-4 weeks and may be given at the same time as ADT and chemotherapy. Bone-targeted therapy may be associated with fatigue, nausea, anemia, and pain.

Most of the research so far has looked at using bisphosphonates with secondary breast cancer, secondary prostate cancer and myeloma. The type of bisphosphonate your doctor prescribes for you will depend on the type of cancer you have. You will have one that works for your type of cancer.

There might sometimes be a choice of bisphosphonates for your type of cancer. Your doctor will give you the bisphosphonate best suited to your medical and practical needs. For example, you might prefer to take a bisphosphonate tablet at home rather than travel to hospital every month for treatment by drip.

### Other Bone-targeted therapy for cancer metastases

The bones are a common place for prostate cancer to spread. Bone-targeted therapy may help men with prostate cancer that has spread to the bones as they may get "skeletal-related events" (SREs). SREs include fractures, pain and other problems. If you have advanced prostate cancer or are taking hormone therapy, your provider may suggest calcium, Vitamin D or other drugs for your bones. These drugs may stop the cancer, reduce SRE's and help prevent pain and weakness from cancer growing in your bones.

**Radiation therapy and ADT** — ADT can often control the cancer that has spread to the bones, however males who develop bone pain in one or a few bones because of the cancer can be treated with radiation therapy to relieve their pain. Radio pharmaceuticals are drugs with radioactivity that give off small amounts of radiation, targeting the exact parts where cancer cells are growing. They may be offered when ADT is not working and can be used to help with bone pain from metastatic cancer. Some may also be used for men whose mCRPC has spread to their bones.

The radiation is usually given in one or a few visits, similar to having an X-ray. Some people have worsened pain for one to two days immediately after the radiation treatment. However, most people feel partial or complete improvement of pain within a week after treatment.

Radium-223 — Radium-223 is a radioactive element that localizes in bone. For males whose advanced prostate cancer consists almost exclusively of extensive bone metastases, treatment with radium-223 is often effective at relieving bone pain, preventing complications (broken bones, need for radiation therapy, spinal cord injury caused by the cancer), and extending life.

While radium-223 is usually combined with ADT, it has not been studied in combination with other therapies, such as chemotherapy or abiraterone, and it is not recommended in combination with these agents.

Males with bone metastases can also benefit from medicines called "osteoclast inhibitors," such as denosumab (brand name: Xgeva) or zoledronic acid (brand name: Zometa). These medicines can help prevent fractures, the need for bone surgery, spinal cord compression, and the need for radiation therapy to treat pain.

**Radiofrequency ablation (RFA)** — Doctors are studying the use of RFA to help control pain in men whose prostate cancer has spread to one or more areas in the bones. During RFA, the doctor uses a CT scan or ultrasound to guide a small metal probe into the area of the tumor. A high-frequency current is passed through the probe to heat and destroy the tumor. RFA has been used for many years to treat tumors in other organs such as the liver, but its use in treating bone pain is still new. Still, early results are promising.

### **Biological Therapy (also known as Immunotherapy or Genetic Therapy)**

**Biological therapy** is a type of treatment that uses substances made from living organisms to treat cancer, essentially using the body's immune system to kill cancer cells. Biological therapy for cancer is used in the treatment of many types of cancer to prevent or slow tumor growth and to prevent the spread of cancer.

Harnessing the Immune System to Fight Off Cancer Cells For the immune system to fight off foreign invaders, it must learn to recognize what's normal and what's not normal. Unfortunately, because cancer cells start out as normal healthy cells, the immune system never has a chance to learn to distinguish between the normal cell and the cancer cell.

Unlike preventive vaccines, which are designed to teach the immune system to develop a way to fight off a specific virus should it encounter that same virus again, therapeutic vaccines stimulate the immune system to recognize and fight certain proteins specific to cancer cells. Each of the therapeutic vaccines currently being tested in men with advanced prostate cancer works in a slightly different fashion, but all are designed to harness the immune system's ability to fight off disease and teach it to fight off prostate cancer cells. One such vaccine, Provenge (sipuleucel-T) was recently approved by the FDA for prostate cancer (see page 66 for more inforamtion on this vaccine).

**Immunotherapy (or genetic therapy)** — Immunotherapy is a type of biological therapy, a newer approach to treating advanced prostate cancer. This is a type of treatment that uses the body's immune system to help slow or stop cancer growth and has the potential to deliver more targeted, less invasive treatments for advanced prostate cancer patients. This could result in fewer side effects and better control of the prostate cancer progression.

**Checkpoint inhibitor immunotherapy** — Another immunotherapy approach is use of a group of medications called "checkpoint inhibitors." An important part of the immune system is its ability to keep itself from attacking other normal cells in the body. To do this, it uses "checkpoints" - proteins on immune cells that need to be turned on (or off) to start an immune response. "Checkpoints" are a built-in part of the immune system intended to prevent it from attacking healthy cells. Checkpoint inhibitors act on certain checkpoints to identify and destroy cancer cells. Several checkpoint inhibitors are used to treat other types of cancer; these work by stimulating cells called "T cells" to attack the cancer.

**Chimeric antigen receptor (CAR) T-cell therapy** In this treatment, immune cells called T cells are removed from the patient's blood and altered in the laboratory, so they have receptors called chimeric antigen receptors (CARs) on their surface. These receptors can be made to attach to proteins on the surface of prostate cells. The altered T cells are then multiplied in the lab and put back into the patient's blood. The hope is that these cells can then find the prostate cancer cells in the body and launch a precise immune attack against them.

This technique has shown some encouraging results against prostate cancer in early clinical trials, but more research is needed to see how useful it can be. CAR T-cell therapy for prostate cancer is a complex treatment with potentially serious side effects, and it is only currently available in clinical trials.

These medications are not yet approved for use in most people with prostate cancer, but they are being studied. They are approved for use in a small subset (1 to 5 percent) of people with prostate cancer whose tumors have specific genetic alterations. Your healthcare provider can tell you if your cancer falls into this category based on testing.

#### SIDE EFFECTS OF IMMUNOTHERAPY

- Skin rash, redness, itching and dryness
- Fever
- Chills
- Nausea or vomiting
- Loss of appetite
- Extreme tiredness (fatigue)
- Fatigue or weakness

- dizziness
- muscle or joint aches
- headache

#### **Combination Therapy Approaches**

In the past, the first treatment for metastatic prostate cancer was ADT alone. Other treatments would be added when the disease became ADT-resistant - that is, when ADT no longer controlled the cancer. Although there are still cases where it's appropriate to start treatment with ADT alone, several studies, beginning in 2017, showed a survival advantage to combining ADT with a more advanced treatment early on, before the disease became ADTresistant. You and your team should discuss the combination treatments that are best for you, looking at relative benefits and side effects.

Hormone Therapy with Surgery — Surgery to remove the testicles for hormone therapy is called orchiectomy or castration. When the testicles are removed, it stops the body from making the hormones that fuel prostate cancer. It is rarely used as a treatment choice in the United States. Men 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 multiple benefits to undergoing orchiectomy to treat advanced prostate cancer. It is not expensive. It is simple and has few risks. It only needs to be performed once. It is effective right away. Testosterone levels drop dramatically.

#### Side effects to your body can include infection and

bleeding. Removing the testicles means the body stops making testosterone, so there is also a chance of the side effects listed for hormone therapy. Other side effects of this surgery may be about body image due to the look of the genital area after surgery. Some men choose to have artificial testicles or saline implants placed in the scrotum to help the scrotum look the same as before surgery. Some men choose another surgery called subcapsular orchiectomy. This removes the glands inside the testicles, but it leaves the testicles themselves, so the scrotum looks normal.

## **IMMUNOTHERAPY** SIDE EFFECTS

The below can be some of the immunotherapy side effects



**Combination Checkpoint Inhibitor and Pharmaceuticals** — One promising approach for the future might be to combine a checkpoint inhibitor with another drug. For example, combining it with a prostate cancer vaccine might strengthen the immune response and help the vaccine work better. Other types of drugs might help the immune system better recognize the cancer cells, which might help the checkpoint inhibitor itself work better.

**Combination Radiation and Endocrine Therapy** — Sometimes, patients receive hormone therapy in combination with external beam radiation therapy for the treatment of prostate cancer. This treatment uses a high-energy X-ray machine to direct radiation to the prostate tumor. For patients with intermediate or high-risk prostate cancer, studies show this combination is more effective at slowing the disease than endocrine therapy or radiation therapy alone.

Radiation can also come in the form of a monthly intravenous drug called Xofigo. Xofigo is approved for use in men who have advanced prostate cancer that has spread only to the bones. Candidates should have also received therapy designed to lower testosterone. The drug works by binding to minerals within bones to deliver radiation directly to bone tumors.

Two other similar drugs are strontium-89 (Metastron) and samarium-153 (Quadramet). If your treatment plan includes radiation therapy, read the SpaceOAR section on page 57.

**Combined approaches with ADT** — Often, ADT is given in combination with another form of treatment, such as:

**Abiraterone** — Abiraterone (sample brand name: Zytiga) is a medication that blocks the production of androgens by the prostate cancer itself, as well as in the testes and adrenal glands. It is often given in combination with ADT, as combined therapy can improve survival (how long a man will live) over ADT alone.

Abiraterone has been shown to improve survival in males with advanced prostate cancer whether they have already been treated with chemotherapy or not. Abiraterone must be taken with a steroid (such as prednisone) to avoid a serious complication. Side effects of abiraterone can include fluid retention, a drop in blood potassium levels, and liver problems.

Enzalutamide, apalutamide, and darolutamide — Enzalutamide (brand name: Xtandi), apalutamide (brand name: Erleada), and darolutamide (brand name: Nubeqa) are other, newer agents that block the effects of androgens in stimulating the growth of the prostate cancer cells.

Enzalutamide has been shown to increase survival in males with metastatic prostate cancer who are no longer responding to hormone therapy alone (known as "castration-resistant" prostate cancer) and who have already been treated with chemotherapy.

In addition, all three drugs (enzalutamide, apalutamide, and darolutamide) have been shown to increase survival in males with non-metastatic castration-resistant prostate cancer who have not yet received chemotherapy, delaying both the progression of the disease and the need for chemotherapy in this setting.

Finally, the addition of either enzalutamide or apalutamide to ADT has led to improved outcomes compared with ADT alone in males with newly diagnosed metastatic prostate cancer who have not yet been treated with ADT ("castration-sensitive" prostate cancer). (See 'Androgen deprivation therapy' above.)

**Secondary hormone therapy** — Even when prostate cancer becomes castration resistant, some form of ADT is continued because at least a portion of the cancer cells might still respond. (See 'Androgen deprivation therapy' above.)

#### SECONDARY HORMONE THERAPY CAN INCLUDE THE FOLLOWING:

- Adding an antiandrogen (such as bicalutamide, nilutamide, or flutamide) in males who have thus far been treated only with GnRH agonists.
- Trying a different type of antiandrogen (eg, enzalutamide or apalutamide).
- steroids, or the antifungal medication ketoconazole.

### **Emerging Therapies**

All around the world, researchers are busy identifying new drugs, new regimens, and new treatment approaches that might prove beneficial to men with prostate cancer. Most of these investigational agents are being tested in men with advanced prostate cancer because treatment options for men at this stage of disease are often not effective, and men are typically affected by side effects from the disease. It is the perfect stage at which to test out new drugs because any improvement will likely be rapidly noticed and much appreciated.

Targeted Therapies are drugs that are specifically designed to interfere with the way cancer cells grow, with the way cancer cells interact with each other, and/or with the way that the immune system interact with the cancer without damaging a man's normal cells. There are several different kinds of targeted therapies being investigated for prostate cancer. None have yet been approved by the FDA for use in prostate cancer, but the excitement generated by some of the early studies have led many researchers to believe that it's only a matter of time before a targeted therapy is found that can result in better overall outcomes.

**Triplet therapy** — At least two studies have shown that combining ADT with six cycles of docetaxel and either darolutamide or abiraterone ("triplet therapy") improves outcomes over ADT plus docetaxel for people whose cancer has already spread outside of the prostate (typically to the bones or other organs). This has become a preferred approach over ADT plus docetaxel alone in males who are candidates for docetaxel chemotherapy and who have "high volume/high risk" disease. Whether a person is considered high volume/ high risk depends on several things, including where the cancer has spread, how many metastases there are, and how aggressive (fast growing) the cancer is.

**PARP** inhibitors — Some men with prostate cancer have mutations in DNA repair genes (such as BRCA2) that make it hard for cancer cells to fix damaged DNA. Drugs called poly-adenosine diphosphate ribose polymerase (PARP) inhibitors work by blocking a different DNA repair pathway. Cancer cells are more likely to be affected by these drugs than normal cells.

**Interfering with Cancer Cell Growth** All cells in the body, including cancer cells, rely on a complex communication system to know when to grow, when to divide, and when to die. This system uses specialized proteins, fats, and other substances to tell the different cells or parts of cells how to act. Over the years, cancer researchers have been studying ways to interfere with the signaling system that regulates the growth of cancer cells.

• Stopping the antiandrogen in males who were treated with combined androgen blockade.

Cancer that is resistant to one antiandrogen treatment may not be resistant to another.

• Trying another medicine that blocks the activity of androgen in the body, including estrogen,

• Abiraterone, which blocks androgens from being made in the tumor and in the rest of the body.

**Interfering with Cancer Cell Spread** As cancer cells divide and start to spread, new blood vessels sprout from the old ones to help supply the necessary nutrients to the new tumor site via a process called angiogenesis. If angiogenesis could be inhibited, researchers theorized, the new tumor cells would die, and the cancer's growth would be halted.

As of 2018, there are now multiple early-phase clinical trials in prostate cancer of antiangiogenic agents. Several of these agents are now in Phase III development. Combined therapy with two antiangiogenic compounds may improve the activity of either compound alone. Multiple targets in the angiogenesis pathway continue to be clarified and should remain an active area of investigation for the treatment of prostate cancer.

PARP inhibitors such as olaparib, rucaparib, and niraparib have shown promising results in early studies of men with one of these gene mutations, and these drugs are now being studied in larger clinical trials.

**Monoclonal antibodies** — These are manmade versions of immune proteins that can be designed to attach to very specific targets on cancer cells (such as the PSMA protein on prostate cancer cells). For prostate cancer, most of the monoclonal antibodies being studied are linked to chemotherapy drugs or to small radioactive molecules. The hope is that once injected into the body, the antibody will act like a homing device, bringing the drug or radioactive molecule directly to the cancer cells, which might help them work better. Several monoclonal antibodies are now being studied in clinical trials.

**Cancer vaccine** — One form of immunotherapy involves the use of a cancer vaccine called "sipuleucel-T" (brand name: Provenge). This vaccine is made by isolating white blood cells (dendritic cells) from the patient's blood and stimulating them outside of the body with various chemicals to build the body's immunity against the cancer. These cells are then re-injected into the patient three different times at intervals of two weeks.

Side effects with this cancer vaccine have generally been mild and include chills, fever, fatigue, nausea, and headache.

**Provenge for Advanced Prostate Cancer** — Sipuleucel-T (Provenge) is a "vaccine" for advanced prostate cancer that helps prolong survival. This is not your everyday vaccine. It's an immune therapy created by harvesting immune cells from a patient, genetically engineering them to fight prostate cancer, and then infusing them back into the patient's immune system.

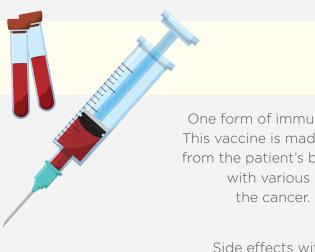
It's approved only for treatment of patients with few or no prostate cancer symptoms whose cancer has spread outside the prostate gland and is no longer responding to hormone therapy.

Once a cancer grows beyond a certain point, the immune system has a hard time fighting it. One reason is that cancer cells look a lot to the immune system like normal cells. Another reason is that tumors may give off signals that manipulate the immune system into leaving them alone.

The Provenge vaccine bypasses these problems. The treatment first removes a quantity of dendritic cells from a patient's blood. Dendritic cells show pieces of tumor to immune cells, priming them to attack cells that carry those pieces.

The patient's doctor ships the cells to Provenge's manufacturer, Dendreon, which then exposes them to the Provenge molecule which is made inside genetically engineered insect cells. Once these cells have been exposed to Provenge, they're shipped back to the doctor who infuses them back into the patient. This is done three times in one month. The first infusion primes the immune system. The second and third doses spur an anticancer immune response.

The most common side effect is chills, which occurs in more than half of the men that receive Provenge. Other common side effects include fatigue, fever, back pain, and nausea. Provenge has been remarkably safe. However, clinical trials suggest that the treatment might be linked to a slightly increased risk of stroke.



Side effects with this cancer vaccine have generally been mild and include chills, fever, fatigue, nausea, and headache.

#### **Clinical Trials**

Clinical trials bring life-extending and curative new treatments to cancer patients. Clinical drug trials play a vital role in moving new treatments to patients who need them most, securing data so that regulatory approvals can be obtained, and new drugs can move into widespread clinical practice. Patients who participate in clinical trials provide an invaluable service both to science and fellow patients.

There are currently over 90 Phase III drug trials and more than 400 Phase I/II trials in process for prostate cancer in North America and Europe. Those that are approved will join the five new drugs that have been approved for men with advanced metastatic disease since 2010 and further improve outcomes for patients:

Jevtana (cabazitaxel) Provenge (sipuleucel-T) Xgeva (denusomab)

The Prostate Cancer Clinical Trials Consortium (PCCTC) is a clinical research group sponsored by the Prostate Cancer Foundation and the Department of Defense Prostate Cancer Research Program (PCRP), with its Coordinating Center headquartered at Memorial Sloan Kettering Cancer Center. The PCCTC is currently composed of 11 participating clinical research sites and 21 affiliated clinical research sites. *Visit the PCCTC site for trial information: www.pcctc.org* 

#### **Possible General Side Effects**

Many men understand that when prostate cancer is caught early, it can be treated effectively, and the primary treatment options for localized disease are all excellent choices. However, many men also have significant concerns about the side

#### cancer vaccine "sipuleucel-T" (brand name: Provenge)

One form of immunotherapy involves the use of a cancer vaccine. This vaccine is made by isolating white blood cells (dendritic cells) from the patient's blood and stimulating them outside of the body with various chemicals to build the body's immunity against the cancer. These cells are then re-injected into the patient three different times at intervals of two weeks.

> Xofigo (radium 223 dichloride) Xtandi (enzalutimide) Zytiga (Abiraterone)

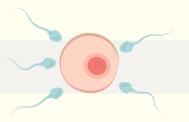
## TRFATMENT SIDE EFFECTS

The below can be prostate cancer treatment side effects.



## Urinary Dysfunction





Loss of Fertility



effects of these treatments. While some side effects may be temporary, others can be permanent and may not improve over time.

- Urinary Dysfunction Erectile Dysfunction Fever **Bowel Dysfunction** Loss of Fertility
- Decreased Sexual Desire Hot flashes and/or Fatigue, Loss of Energy and/or Memory

Not all side effects occur in every patient since they depend on the type of treatment and the individual patient response. Some side effects may significantly impact the man with prostate cancer and his family, so it is important to keep an open dialogue with your doctor about the potential side effects of each treatment.

The concerns are justified, but there are many misunderstandings about how often side effects occur, how severe they really are and what can be done to manage them and counteract their occurrence. Early management of side effects has been shown to help patients live longer, better lives. Is it also of extreme importance that you communicate with your doctors about the side effects that you are experiencing as you undergo treatment. Ongoing and proactive communication will enable your doctor to manage your side effects as early as possible to prevent worsening or development of downstream complications.

**Urinary Dysfunction** A large proportion of men experience urinary issues in association with surgery or external beam radiation therapy (EBRT). The most common urinary issue after surgery is incontinence, or the inability to control the flow of urine from the bladder. Generally, the degree of incontinence will improve over the first year following surgery, but some men may be left with a permanent problem. There are procedures (ex. slings and artificial urinary sphincter implants) that can help men with permanent or bothersome urinary incontinence. Additional urinary issues include pain or difficulty urinating, an urgency to urinate, and hematuria (blood in the urine); these may be more common after radiation therapy for prostate cancer.

**Erectile Dysfunction** Following surgery or radiation therapy, as well as during hormonal therapy, most of prostate cancer patients experience some degree of erectile dysfunction (ED) - the inability to attain and/or maintain an erection that is sufficient for satisfying sexual activity. Newer, surgical nerve-sparing techniques used during surgery for certain patients can reduce some of this side effect, but it is common for at least some degree of ED to be present after treatment. If ED becomes a problem, your doctor can prescribe ED medications that can be helpful for some patients.

**Bowel Dysfunction** Fecal incontinence (also referred to as bowel dysfunction) is the inability to control defecation (bowel movements). It may occur in patients who undergo radiation therapy, especially external beam radiation therapy (EBRT). This is typically a short-term side effect and less common in the modern era of radiation treatment.

Proctitis (the inflammation of the rectum and anus) is an issue most men undergoing EBRT will experience; it includes some degree of irritation to the rectum during treatment and sometimes bleeding from the rectum/anus. For most men, this is temporary and can be treated with suppositories and gentle enemas.

Loss Of Fertility Loss of natural fertility and ejaculation is an unavoidable side effect of surgery (radical prostatectomy). Loss of fertility may also occur in association with radiation therapy and chemotherapy due to disruption of normal semen production and ejaculation. Hormone therapies such as ADT and particularly surgical castration also produce complete infertility. For this reason, prostate cancer patients who wish to father children in the future may elect to bank their sperm.



## Visit the resource center of the IPCF website for prevention tips, support groups, and more!

Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

There are many things that men can do to aid in the recovery and treatment of prostate cancer.

www.fightingprostatecancer.org/resources-1



## FIT PEOPLE HAVE ADOPTED HEALTHY habits and practice them with discipline

In general, doctors recommend that men make choices that benefit their overall health. Below are some things that have shown some evidence of lowering your prostate cancer risk.





SAFFLOWER, SOYBEAN USE HEALTHY OILS

#### AVOID FRIED FOODS. EAT BROILED OR BAKED FISH. OPT FOR STEAMED, GRILLED, OR BROILED DISHES AT RESTAURANTS



# 5. STRATEGY FOR FIGHTING & PREVENTING PROSTATE CANCER WITH HEALTH, NUTRITION & EXERCISE

### **Monitoring For Recurrence**

After initial treatment for localized or locally-advanced prostate cancer is complete, the next phase in the process is monitoring for a recurrence, or a regrowth of the cancer cells somewhere in your body. Monitoring for recurrence typically involves PSA testing, which

is repeated every 6 months for the first 5 years, then yearly from that time on. A prostate exam is typically performed every year as well but may be omitted if the PSA level is undetectable. If your PSA starts to rise, it could be a sign of your cancer returning.

#### **Mental Health**

Your psychology, or state of mind has played, and will continue to play, a critical role in your cancer journey. From staying positive to controlling your diet and exercise routine, your overall mental health is a cornerstone in the ongoing treatment and control of your disease. You may experience new or difficult feelings about your situation. You do not have to face this alone.

Just as with your diagnosis, and regardless of which treatment option you choose, you may experience new or difficult feelings about your situation. This is normal.

Living with prostate cancer can affect the way you view yourself and it can affect your interactions with the world around you. As always, it's important to check in with yourself and seek help from your team of doctors, friends and family. Many patients choose to proactively attend support groups with other patients or begin working with a mental health practitioner. Others feel more comfortable connecting one-on-one with another prostate cancer survivor. Everyone is different in terms of what he needs and how these needs can best be met.

The most important thing is to periodically assess yourself carefully and reach out in ways that will work for you. Check with the hospital or cancer center where you received treatment for referrals to counseling services, often free, for patients living with prostate cancer.

### **Maximizing Quality Of Life**

As a man with prostate cancer, you may have significant concerns about the side effects of treatment. It is important to communicate with your doctor about your questions and concerns, both when choosing between treatment options, and

when undergoing treatment. Find out from your treatment team whether they have recommendations for ways to modify behavior that can reduce or help you avoid specific side effects.

There are many misunderstandings about how often side effects may occur, how severe they really are or should be, and what can be done to manage them and counteract their occurrence. Many of the side effects that men fear most following local treatment are less frequent and severe than they might think. This is due to:

- Technical advances in both surgery and radiation therapy
- Researchers persistently seeking new ways to help overcome side effects
- Improvements in treatment delivery methods. It's still important to understand how and why these effects occur, and to learn how you can minimize their impact on your daily life. It is important to have frank conversations with your doctors about the complications you most want to avoid and consider treatment options in terms of the likelihood of the risks of these complications.





#### **Prevention**

Visit the resources section for prevention tips, support groups, and more! fightingprostatecancer.org

There are many things that men can do to reduce or delay their risk of developing prostate cancer.

Why is prostate cancer so common in the Western culture and much less so in Asia, and why when Asian men migrate to western countries? It is believed the major risk factor is diet – foods that produce oxidative damage to DNA.

What can I do to prevent or delay the onset of the disease? There's no sure way to prevent prostate cancer. Study results often conflict with each other and most studies aren't designed to definitively prove if something prevents prostate cancer. As a result, no clear ways to prevent prostate cancer have emerged. In general, doctors recommend that men with an average risk of prostate cancer make choices that benefit their overall health.

Below are some things that have shown some evidence of lowering your prostate cancer risk.

**Exercise** can help you maintain your weight, or it can help you lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce your risk of heart disease and other cancers. If you are overweight or obese, work on losing weight. You can do this by reducing the number of calories you eat each day and increasing the amount of exercise you do. If you have a healthy weight, work to maintain it by exercising most days of the week and choosing a healthy diet that's rich in fruits, vegetables and whole grains.

If you don't already exercise, make an appointment with your doctor to make sure it's OK for you to get started. When you begin exercising, go slowly. Aim for 30 minutes of exercise most days of the week.

**Reduce Fat** Try to keep the amount of fat you eat from red meat and dairy products to a minimum. In some studies, men who ate the highest amount of fat each day had an increased risk of prostate cancer. While this association doesn't prove that excess fat causes prostate cancer, reducing the amount of fat you eat each day has other proven benefits, such as helping you control your weight and helping your heart stay healthy.

To reduce the amount of fat you eat each day, limit fatty foods or choose low-fat varieties. For instance, reduce the amount of fat you add to foods when cooking, select leaner cuts of meat, and choose low-fat or reduced-fat dairy products. In studies, men who ate the most dairy products — such as milk, cheese and yogurt — each day had the highest risk of prostate cancer. But study results have been mixed, and the risk associated with dairy products is thought to be small.

**Make Smarter Food Choices** Eat more fish. Evidence from several studies suggest that fish can help protect against prostate cancer because fish have "good fat" such as omega-3 fatty acids. Avoid trans fatty acids (found in margarine).

Try to incorporate tomatoes that are cooked with olive oil, which has also been shown to be beneficial, along with cruciferous vegetables (like broccoli and cauliflower) into many of your weekly meals.

Eat more fat from plants than from animals. In studies that looked at fat consumption and prostate cancer risk, fats from animals were most likely to be associated with an increased risk of prostate cancer. Animal products that contain fats include meat, lard and butter.

You might consider using plant-based fats instead of animal fats. For instance, cook with olive oil rather than butter. Sprinkle nuts or seeds on your salad rather than cheese. Soy and green tea are also potential dietary components that may be helpful, as well as broccoli, pomegranate juice, tomatoes and legumes.

**What about supplements?** Avoid over-supplementation with megavitamins. Too many vitamins, especially folate, may "fuel the cancer", and while a multivitamin is not likely to be harmful, if you follow a healthy diet with lots of fruits, vegetables, whole grains, fish, and healthy oils you likely do not even need a multivitamin. Watch your calcium intake. Do not take supplemental doses far above the recommended daily allowance. Taking calcium supplements is fine but avoid taking more than 1,500 mg of calcium a day. Always check with your healthcare team before taking anything on your own.

Seek medical treatment for stress, high blood pressure, high cholesterol, and depression. Treating these conditions may save your life and will improve your survivorship with prostate cancer. A yearly rectal examination and PSA test will also go a long way in early detection or diagnosis.

**Relax and enjoy life.** Reducing stress in the workplace and home will improve your survivorship and lead to a longer, happier life.

#### **Healthy Body**

According to the Centers for Disease Control and Prevention (CDC), the number one cause of death in men of all ages was cardiovascular disease (CVD). Killing 321,000 men in 2013 — that's 1 in every 4 male deaths. That means preventing CVD is an important thing you can do for your health; regardless of whether you have prostate cancer. Fortunately, you can do something to improve your heart health—start by increasing regular exercise, eating right and checking your cholesterol and blood pressure.

In fact, knowing your cholesterol and blood pressure numbers is just as important as knowing your latest PSA results. With your doctor's advice, making simple changes to your eating habits and exercise regimen can help make a difference in your overall heart health.

#### Watch Your Cholesterol

It is important to monitor your cholesterol levels through regular testing to be sure your heart is healthy. Cholesterol test results include your total cholesterol level, which is a combination of 3 things:

LDL (bad cholesterol) + HDL (good cholesterol) + Triglyceride level (blood fats)

Cholesterol numbers can help predict your risk of heart disease. They can also let you know if lifestyle changes, such as changes in your diet and starting an exercise program should be considered.

Talk to your doctor about what your cholesterol numbers mean. You can also learn more about taking care of your heart from the American Heart Association.

#### **Check Your Blood Pressure**

Have your blood pressure levels monitored regularly to ensure good heart health. Blood pressure levels can let you know how well your changes in lifestyle are working. Optimal blood pressure levels may also lower the risk for some abnormal prostate conditions.

Definitions to Understand: Systolic is the measurement of blood pressure when your heart contracts. Diastolic is the measurement of blood pressure when your heart relaxes and expands.

#### **Blood Pressure Levels**

Normal: Systolic: less than 120 mm Hg Normal: Diastolic: less than 80 mm Hg At risk (prehypertension): Systolic: 120–139 mm Hg At risk (prehypertension): Diastolic: 80–89 mm Hg High: Systolic: 140 mm Hg or higher High: Diastolic: 90 mm Hg or higher

#### Permanent Upgrades To Healthy Living

From the moment you are diagnosed with prostate cancer, it's important to make mindful decisions about your diet and lifestyle. Your everyday choices are vital to the success of your treatment and your recovery from the disease, and it's a great way to take back some of the control that cancer and its treatment may have had on your life. Additionally, there is growing scientific evidence that suggests healthy diet and lifestyle practices may actually slow the growth and progression of prostate cancer.

#### **Nutrition To Boost Immunity**

Nutrition is an important part of cancer treatment. From changes in taste, to appetite loss and overall fatigue, you may face several challenges. This is common for people living with cancer.

Balancing your diet can be a challenge at the best of times, but when going through a cancer journey it is even more important. The right balance of proteins and calories can help your body stay strong and healthy — before, during, and after cancer treatment.

Watch for key changes in: Body weight Muscle mass Calorie intake

Eating in a healthful manner may help to keep your strength up through a treatment course, provide more energy to spend time with family and friends or be productive at work. It may be important to consider working with a registered dietitian to help with specific nutritional needs.

## BOOST THE IMMUNE SYSTEM

The below have shown to give support to immunity.

beta-carotene and zinc



eat plant based foods

ge an

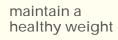
get a sufficient amount of sleep

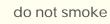
cook meats thoroughly

wash your hands frequently

minimize stress

exercise regularly





alcohol in moderation, if at all.

visit the ipcf RESOURCES CENTER to download a shopping list of prostate cancer healthly foods **Check with Your Doctor** It's important to talk with your doctor before embarking on any major changes to your diet, including taking any vitamins or supplements on your own. Some vitamins and supplements can affect your prostate cancer treatment.

**You Are What You Eat** When you eat healthy food and exercise, your whole body is affected in a positive way. A healthier lifestyle means making smart choices whenever possible. Below are some things to keep in mind regarding your nutrition.

**Count Your Calories** To maintain your weight, monitor your intake of fat calories.

**Read nutrition labels** NO foods high in total fat, saturated fat, & cholesterol. Watch your portion sizes: Do not overeat. Eat smaller portions of food.

Choose the most nutritionally rich foods you can from each food group each day — low calorie foods packed with vitamins, minerals, fiber and other essential nutrient.

**Eating fiber-rich foods** — for example: beans, fruits, vegetables, bran cereals, flaxseed, whole grains, and oats — can help many areas of your body, such as heart, prostate, and digestive health. There are several benefits to adding fiber to your diet, including helping to make you feel full, which can help control your weight. It can lower cholesterol, improve your blood sugar balance, make bowel movements easier and can reduce the risk of digestive problems.

How much fiber should you have? If you are a man older than 50 years, 30 grams a day should be your goal.

**Flaxseed & Soy** Flaxseed is high in fiber, omega-3 fatty acids, and phytochemicals called lignans. Flaxseed (and its oil) is used as a laxative, to help improve digestive health, relieve constipation, and reduce the risk of heart disease. The addition of soy protein to a diet low in saturated fat and cholesterol may help to reduce the risk of heart disease.

**Omega Fatty Acids (Unsaturated Fats)** Omega Fatty Acids are thought to be good for your overall health and may be good for your prostate health as well. Increase cold water fish, flaxseed, walnuts, soybeans and canola oil. Bake or broil fish and avoid eating fried fish as the trans fats in fried foods are unhealthy. Some studies have shown eating fish 3 times a week lowers your risk of prostate cancer.

#### Diet

Just a few simple changes in your daily eating habits can help support healthier living as you recover from prostate cancer and may even decrease risk of your cancer coming back or getting worse. All these recommendations also apply to maintaining overall health, for you and your family. *See the PREVENTION SECTION on page 05 and 72 for eating tips, nutrition guidance, and more.* 

#### **Exercise**

Exercise is part of a healthy lifestyle for everyone. For prostate cancer survivors, exercise as much as you are physically able, at a pace which is maximal for your personal fitness.

For those who can exercise vigorously, walk as briskly as you can (3+ miles per hour), and try to add bouts of jogging. Vigorous exercise should include close to maximal effort, in which your heart beats rapidly and you are sweating. Such activity includes running, vigorous swimming, or fast bicycling.

Research suggests that exercise affects energy metabolism, inflammation, oxidative stress, immunity, and androgen signaling pathways, and is therefore beneficial for men with prostate cancer.

Exercise reduces levels of inflammation. Several studies have shown that vigorous exercise significantly reduced the risk of prostate cancer recurrence, compared with the same volume of exercise at an easy pace.

#### Lifestyle Changes

In addition to diet and exercise, several other lifestyle factors may be associated with prostate cancer risk and progression.

**Smoking** Quitting smoking may reduce the risk of dying from prostate cancer and reduces the risk of dying from any cause. The health benefits from quitting begin on the first day after smoking ceases. Recent evidence further suggests that smoking is associated with more aggressive prostate cancer at the time of diagnosis. Furthermore, smokers have a higher risk of prostate cancer progression, including recurrence and metastasis, as well as an increased likelihood of death. Importantly, when compared with current smokers, men who quit smoking more than 10 years ago had prostate cancer mortality risk similar to those who have never smoked.

## Visit the resource center of the IPCF website for recipes, workouts and mindful strategies to sustain long-term healthy changes!



## DO NOT CUT OUT FAT ALTOGETHER YOUR BODY NEEDS THESE NUTRIENTS. EAT IN MODERATION.









#### **Staying Fit**

Besides making healthy choices in your diet, men being treated for prostate cancer should start an exercise routine. Resistance exercise can help reduce symptoms of fatigue related to prostate cancer treatment. Exercise also strengthens muscles that may have become weakened with hormone treatments.

Before starting any exercise program, always talk with your doctor to ensure that your program is safe for your physical condition.

There are many reasons why we tend to slow down and become more sedentary with age. It may be due to health problems, weight or pain issues, or perhaps you think that exercising simply isn't for you. But as you grow older, an active lifestyle becomes more important than ever for your wellbeing.

**Exercise Daily** Exercising for as little as 30 minutes a day can help improve your health. You may even be able to reduce some of the side effects related to prostate cancer treatments by being physically active. Tip: Exercising with friends is both social and motivating. Exercise can help boost your energy, maintain your independence, protect your heart, and manage symptoms of illness or pain as well as your weight.

Daily exercise is also good for your mind, mood, and memory. Becoming active is not just about adding years to your life, but about adding life to your years. You'll not only look better when you exercise, you'll feel sharper, more energetic, and experience a greater sense of wellbeing.

Take the Lifestyle Assessment The International Prostate Cancer Foundation has developed a great tool for assessing your baseline health. You may want to print the results and share them with your doctor. Together, you'll be able to discuss the next steps you should take toward a healthier lifestyle. This baseline will also help you know when you are making improvements! Take the quiz online, or in the next section of this guide.

#### **Take The Lifestyle Assessment**

Your lifestyle is a habit that dictates how fit and healthy you will be. The International Prostate Cancer Foundation has developed a great tool for assessing your baseline health. You may want to print the results and share them with your doctor. Together, you'll be able to discuss what steps toward a healthier lifestyle you should take next. And this baseline will help you know when you are making improvements!

Answer honestly. The assessments purpose is not for guilty feeling or shame. Its purpose is to help you see where you are and if you are in the right mindset for lifestyle changes and commitment. The results may surprise you, but they can also point you to how you can improve both your physical and mental health. Remember the benefits of a healthy lifestyle far outweigh the effort. The body achieves what the mind believes.

# **12 Easy Questions**

Be sure to record your score!

Give yourself 4 points for each a	Gi
Give yourself 2 points for each b	Gi

1. Do You Exercise? (light to moderate	te activity for 30
a. everyday	c. once or
b. once or twice a week	d. hardly e

. never	c. occasio
. quit years ago	d. everyda

#### 3. How Fit Are You?

a.

b.

- a. very fit, I eat right, no processed foods at all and exercise daily
- b. relatively fit, I eat mostly healthy, some processed foods and exercise weekly
- c. below average, I eat mostly processed foods and sometimes exercise
- d. totally unfit, I eat mostly processed foods and never exercise

#### 4. Are You Overweight?

- a. no, i am where my doctor thinks I should be
- b. yes, but I have started a wellness and fitness plan
- c. yes, i am aware but haven't begun to get fit yet
- d. yes, and I really don't think it's a big deal

#### 5. How Many Meals Do You Eat a Day?

- a. several smaller balanced snack type meals throughout the day
- b. 3 balanced meals with portion control
- c. 3 large unbalanced meals
- d. less than 2 times a day



Give yourself 1 points for each c Give yourself 0 points for each d

- 0 minutes)
- twice a month
- ever/never

2. Do You Smoke or Use Tobacco Products? (including cigarettes, cigars, chewing tobacco, e-cigarettes)

- onally
- ay

#### 6. Do You Drink Alcohol?

a. not at all	c. occasionally
b. seldom	d. everyday

7. How Many Times Do You Eat Out?

- c. five or six times a week a. zero to two times a week
- b. three or four times a week

d. more than 7 times

#### 8. How Many Hours of Sleep Do You Average?

a. seven or eight	c. over nine
b. five or six	d. less than five

#### 9. Which Statement Best Describes Your Current Feelings on a Healthy Diet?

- a. I buy and prepare a balanced a nutritious diet on a regular basis.
- b. I am currently trying to eat healthy and have a plan in place.
- c. I know that eating healthy would benefit me, but it's hard to stick to it.
- d. The flavor of my food is more important than it's nutritional value.

#### 10. What Do You Do for Leisure and/or Relaxing?

a. outdoor activities, meditation, exercise, reading, gardening, etc

b. drinking, eating out, gossiping, etc

c. movies, surfing the internet, watching tv, etc

d. free time? I don't have that

11. Do You Suffer from Any Mental Conditions? (anxiety, depression, insomnia, mood swings, etc)

#### a. never

b. yes, but i am undergoing treatment and have it regulated

c. yes, quite often and am just starting to seek treatment

d. yes, occasionally and I do nothing to treat it

## 12. Do You Suffer from Any Illness or Diseases? (high blood pressure, diabetes, heart disease, cancer, etc) a. no, i get regular check-ups b. yes, but I am under doctor care and treatment c. yes, it's serious and i am not undergoing treatment

d. i haven't been to the doctor, I don't know

#### **Lifestyle Assessment Results**

Whatever your results, bear in mind that prevention is always the better path. Do not substitute these results for any kind of medical advice or prognosis. This assessment is for understanding the bigger picture of your lifestyle. And will help you decide if you are ready to commit to changing your lifestyle and reaching your goals.

**48-35** You are a **HEALTH NUT!** Congratulations you have some serious discipline. You try your best to live a healthy life and your health is always in tip top condition. You probably see a doctor regularly, and are very proactive about your health. Well done and keep up the good work, but don't forget to engage in some self care and recovery during your fitness journey.

**34-23** You are a relatively healthy! Congratulations you live a very healthy and balanced lifestyle. You have a loose plan, and keep yourself mostly to it. Allowing a little liberty to let loose. Don't let yourself slack, you can always set goals and improve to stay on track.

22-11 Although you realize health is important, you aren't living as balanced as you **could be.** You indulge in life pleasures and temptations very easily, putting your health on the back burner. It's time to be mindful. You can do it. Set an intention. Make a Plan. When you earn your body, you look and feel great!

**10-0** Chances are your body has been sending signals of health problems. Your health is low priority and your choices are not conducive to a healthy balanced lifestyle. It's not too late. Take small steps and you'll be on the right path before you know it.

#### **Do You Hate To Exercise?**

You're not alone if you dislike exercise. Or maybe you just think that exercise is boring. The good news is, you don't have to exercise until you're soaked in sweat or every muscle aches to make a big difference to your health. Think about activities that stimulate joy and how you can incorporate them into an exercise routine:

Listen to music, a podcast, or an audiobook while you walk.

Get competitive while playing tennis.

Take a dance class.

Take photographs or birdwatch on a nature hike.

Meet new people at a yoga class or fitness center. Watch a favorite movie or tv show while on the treadmill. Chat with a friend while stretching or walking. Play golf. Leave the Cart. Walk the Course. Walk or play with your pet - (no pet? Volunteer at a shelter or rescue).

Find an exercise buddy, try activities you've never tried before.

#### Still hate the idea? Change your perspective, sometimes a change of habit is necessary. Try the ideas below.

Is Something Holding You Back? Identify what it is you dislike. Is it the exertion, the sweating, the societal implications of fitness or body issues? Pay attention to your response, but also experiment, with the goal of developing a pleasant routine. Once you identify the part of the process you dislike, you can make adjustments to your routine. For example, if sweating is the issue; choose an exercise that is low impact where you are less likely to sweat, like swimming or ballroom dancing.

Are you Making Excuses? Do you have 10 excuses ready when workout time comes along? Excuses are rationalizations we make to ourselves about people, events, and circumstances. They are invented reasons we create to defend our behavior, to postpone taking action or simply as a means of neglecting responsibility.

Excuses are mainly a means of placing the blame of an internal problem on an external condition. The fact remains that more excuses you make, the harder it will be to motivate yourself. A way to combat this is trying making goals instead of excuses. People who exercise regularly report that they come to rely on it and crave more. You could possibly join that club—once you get started, but first you'll need to find exercise that works well for you.

Tailor it to Personality, Make It Fun Just because it's fun and has a social element doesn't mean it can't "count" as exercise. There is no such thing a "real" exercise. A huge array of activities can make it possible for everyone to find a routine that they genuinely enjoy. Enjoyment will make it easier to turn activities into routine exercise.

#### Make It a Non-Negotiable Part Life

Whatever the activity, make sure it works for these three things: lifestyle, routine, and budget. Schedule it into your daily life as a non-negotiable, like brushing your hair or dressing, so that it's harder to break from the routine than it is to stick to it.

**Do What You Love** You should exercise enough to achieve or maintain a healthy weight. A good way to get started is to find exercises or activities that you enjoy, such as: yoga, powerwalking, swimming, riding a bicycle, dancing, gardening, etc. The important thing is to stay active and keep moving, without overdoing it. A good rule is to exercise enough so you breathe hard but are still able to carry on a conversation.

Make a strategic exercise plan and remember: Don't start with something big. Instead start with what feels good. That's the best recipe for success!

#### **Support And Mental Health**

Cancer can certainly make it difficult to feel engaged or connected to the moment. For patients who have been diagnosed with advanced cancer or facing end-of-life issues, their mind can be so full of worry and stress that they struggle to be present and aware of the time they have right now. Fortunately, there have been many advances and patients are finding alternative ways to cope with both the physical and emotional challenges that come with this disease.

Although it's natural for the prostate cancer patient/survivor and loved ones/caregivers to feel many emotions including anxiety, fear and frustration, it's important to take charge of managing the disease and to recognize that knowledge is power. Below are some tips that can reduce some of the anxiety and confusion that comes with a diagnosis of prostate cancer.

## Visit the resource center of the IPCF website for recipes, workouts and mindful strategies to sustain long-term healthy changes!



Normalizing some emotions allow patients and caregivers to organize their coping resources and attend to self care more efficiently. Many from both groups also report the opportunity to clarify thoughts & feelings enhanced their coping abilities.



Some cancer patients report



Build relationships, laugh and connect. Research shows staying connected and laughing can combat sadness.

# the benefits of therapy XTEND FAR BEYOND PERIODS OF CRISIS



feelings of loneliness & isolation.



## redefine COMMUNITY

Being surrounded by friends who love you can increase your happiness & outlook. Join club or support group.

**Learn** The International Prostate Cancer Foundation site offers a complete overview of information about the prostate, prostate cancer, and its treatment, and educational materials. Visit the Education Center or the Resources Center at fightingprostatecancer.org to guide you through this journey.

**Communicate** A diagnosis of prostate cancer can lead to feelings of fear, anxiety, and depression. Your loved one will need understanding and listening without judgment. Do not pressure him to talk about his feelings before he is ready. Just knowing that you are there for him when he needs you can make a big difference to his sense of emotional wellbeing.

**Participate** Ask patient if he would like support at doctor appointments and tests. Men often do not like to discuss their health, and your loved one may benefit from your presence as an advocate who can help voice concerns to the doctor. Also, being educated about the disease and the treatment options can help. Be prepared with questions to ask the doctor about the disease and treatment options. Find out what kind of side effects may occur after treatment and how they may affect quality of life for him and impact others.

**Find Community** Some caregivers find it helpful to go to therapy or join a support group. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges.

National Association for Home Care & Hospice nahc.org or 202-547-7424

National Family Caregivers Association 301-942-6430 or 800-896-3650 nfcacares.org

#### **Mindfulness & Meditation**

Recently, more people have recognized mindfulness and mindfulness training as a way to decrease stress and increase psychological functioning with cancer patients. A study in 2011 found that most participants expressed a number of positive effects after participating in the mindfulness program. These including increased calm, enhanced sleep quality, more energy, less physical pain, and increased well-being. These findings show that through mindfulness, you may be able to enhance your capacity to handle the life stresses that affect the body's ability to heal.

*Mindfulness* is described as a practice that is about living life as if it matters, to pay attention with kindness and respect to moment-to-moment experiences, no matter how seemingly mundane. Mindfulness can help us to experience life with greater clarity, balance, and gratitude, one moment at a time.

One of the many benefits of practicing mindfulness is that it can promote healing, both physically and emotionally/ psychologically. By helping to regulate emotions and allowing a patient to work with the physical pain in the body, mindfulness has helped bring a sense of peace to many people living with cancer.

Here are some tips on how you can practice mindfulness and the benefits therein.

Make Gratitude A Part of Your Routine. Work on Your Breathing. Meditation. Increase Your Awareness. Watch the World Go By. Take Control of Your Thoughts. Take 10 Minutes to Do Nothing.

*Meditation* is a means of transforming the mind and is described as the written, spoken, or internal dialogue expressing considered thoughts on a subject. It can be done anywhere, for any amount of time, without special equipment or clothing and minimal training. Meditation practices are techniques that encourage and develop concentration, clarity, emotional positivity, and a calm seeing of the true nature of things. By engaging with meditation, you can learn the patterns and habits of your mind, and the practice offers a means to cultivate new, more positive ways of being.

More than 3,000 scientific studies have been conducted on the benefits of meditation, and include positive outcomes for the treatment of depression, anxiety, lack of concentration, high blood pressure, inflammatory disorders, asthma, PMS, Arthritis, Fibromyalgia and more.

Many doctors encourage patients to incorporate this ancient practice into their lives to promote well-being, positive outlooks and even faster recoveries. Research has shown that eight weeks of mindfulness meditation may elevate serum serotonin levels – a compound in the brain that can affect mood and social behavior, appetite and digestion, sleep, memory and sexual desire and function – resulting in a significant decrease in depression, anxiety and stress as well as decreased acute or chronic pain. With regular work and patience these nourishing experiences can have a transformative effect and can lead to a new understanding of life.

In 2014, a breakthrough Canadian study conducted by researchers at the University of Calgary, (Alberta) and Alberta Health services concluded that meditation may be a powerful complement to treatment plans aimed at altering the cellular activity of cancer survivors. The study, which was published in the journal Cancer, was one of the first to suggest scientifically, that a mind-body connection does exist.

#### Here are some tips on how you can practice meditation and the benefits therein.

Find Your Space. Set up a meditation space.
Find Time. Choose a time when your mind is calm.
Establish a Routine.
Be Comfortable.
Remember to Breathe.
Detach yourself from every-day worries.
Focus.
Observe.
Meditate.

#### **Communities & Support Groups**

A support group is a gathering of people who share a common health concern or similar issues, whether that's, relationship problems, major life changes or illness, such as prostate cancer, diabetes, heart disease, addiction or long-term caregiving. A support group shouldn't replace your standard medical care, but it can be a valuable resource to help you cope.

Support groups are not the same as group therapy sessions. Group therapy is a formal type of mental health treatment that brings together several people with similar conditions under the guidance of a trained mental health provider.



# SUPPORT GROUPS & talk therapy CAN HELP BOTH PATIENTS & CAREGIVERS

Talk therapy helps patients & caregivers to develop the tools and strategies for coping. Group therapy participants note that after only a few sessions, they felt better. Other benefits known are: gaining empowerment, gaining a sense of control and reducing distress, depression, anxiety and fatigue.

These groups may be formed by a lay person with the condition or by someone interested in it, such as a family member. In some cases, support groups may be formed by nonprofit organizations, advocacy organizations, mental health clinics or other organizations.

They also come in a variety of formats, including in person, on the Internet or by telephone. They may be led by professional facilitators — such as a nurse, social worker or psychologist — or by group members.

**Online Communities** There are numerous prostate cancer communities and support groups that you can find online. Facebook, Twitter and Google are just a few ways in which to search for, follow, and participate in these support groups and communities.

Organizations that offer online social networking communities and support groups for prostate cancer often display social media icons. Simply click on those icons to join or follow.

**Understanding Support Groups** Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same situation.

While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges.

Benefits of Support Groups Members of a support group offer one another emotional comfort and moral support, while being a great source of information and encouragement. They may also offer practical advice and tips to help you cope with your prostate cancer treatment or diagnosis and more. Such as:

Feeling less lonely, isolated or judged Gaining a sense of empowerment and control Improving your coping skills and sense of adjustment Talking openly and honestly about your feelings Reducing distress, depression, anxiety or fatigue Developing a clearer understanding of what to expect with your situation Getting practical advice or information about treatment options Comparing notes about resources, such as doctors and alternative options Gain instant camaraderie and support A chance to talk about your disease and ask questions Help coping with advanced prostate cancer, such as how to share news of your disease with others Help dealing with practical problems, such as getting to and from doctor visits

A supportive environment to recognize milestones in treatment

How to find a Support Group What support group, if any, you ultimately choose may depend largely on what's available in your community, whether you have access to a computer or whether you're able to travel.

Plan to attend a few support group meetings to see how you fit in. If the support group makes you uncomfortable or you don't find it useful, try another one. Remember that even a support group you like can change over time as participants come and go. Periodically evaluate the support group to make sure it continues to meet your needs.

worker, chaplain or psychologist may be able to recommend a support group for you.

and social networking sites, such as Facebook.

in your area and ask about support groups.

support resources.

for support group suggestions.

or situation.

don't feel it's a good fit — find another group to try.

- Ask your doctor or other health care provider for assistance. Your doctor, nurse, social
- **Search the Internet.** Online support groups are available as email lists, newsgroups, chat rooms, blogs
- **Contact local centers.** Contact community centers, libraries, churches, mosques, synagogues or temples
- **Check your local listings.** Look in your local telephone book or check your newspaper for a listing of
- **Ask people you know with the condition.** Ask others you know with the same illness or life situation
- **Contact organizations.** Contact a state or national organization devoted to your disease, condition
- Be aware that you may be at a different stage of coping or acceptance than are others in the support group. Or they may have a different attitude about their situation. Don't feel obligated to keep attending the group if you

Getting the Most Out of a Support Group When you join a support group, you may be nervous about sharing personal issues with people you don't know. At first, you may benefit from simply listening. Over time, though, contributing your own ideas and experiences can help you get more out of a support group.

Remember that support groups aren't a substitute for regular medical care. Let your doctor know that you're participating in a support group. If you don't think a support group is appropriate for you, but you need help coping with your condition or situation, talk to your doctor about counseling or other types of therapy.

#### Lifestyle Changes

**A Balanced Exercise Plan** Mixing different types of physical activity helps both to keep your workouts interesting and improve your overall health. The key is to find activities that you enjoy—based on the four building blocks of fitness. These are: balance, cardio, strength & power training, flexibility.

Balance maintains standing and stability, whether you're stationary or moving around. Yoga, Tai Chi, and posture exercises will aid in having confidence with balance.

Cardio get your heart pumping. Helps lessen fatigue and shortness of breath. Promotes independence by improving endurance. Includes walking, stair climbing, swimming, hiking, cycling, rowing, tennis, and dancing.

Strength & Power Training repetitive motion using weight or external resistance from body weight, machines, free weights, or elastic bands. Strength training helps prevent loss of bone mass, builds muscle, and improves balance—both important in staying active and avoiding falls. Power training can improve your speed. Building strength and power will help you stay independent and make day-to-day activities easier such as opening a jar, getting in and out of a car, and lifting objects.

Flexibility helps your body stay limber and increases your range of movement for ordinary physical activities. This can be done through stationary stretches and stretches that involve movement to keep your muscles and joints supple and less prone to injury. Yoga is an excellent means of improving flexibility, as well as water aerobics/sports, walking and Qi Gong.

Experiment with Mindfulness Instead of zoning out when you exercise, try to focus on how your body feels as you move — the rhythm of your breathing, the way your feet strike the ground, your muscles flexing. You'll improve your physical condition faster, better help to relieve stress and anxiety, and more likely to avoid accidents or injuries.

Commit to an Exercise Schedule Follow a regular schedule for at least 3 or 4 weeks so that it becomes habit. This is much easier if you find activities you enjoy.

#### **Recovery & Self Care**

Recovery after exercise is essential to muscle and tissue repair and strength building. This is even more critical because aging and cancer treatments change the body. Keep this in mind when building your exercise plan, pace out your sessions well. Don't feel guilty about taking time out to recover. Limited research reports suggest that with increasing age muscles tend to recover more slowly after a bout of exercise, whether it is strength or endurance training. Therefore, rest and hydration are essential after exercise, especially as aging sets in.

Here are some tips on how you can aid the body in recovery.

Drink Water.

Eat healthily both before & after exercise. Consume 30-40 grams of high-quality protein after exercise. Drink a glass of milk or eat a handful of nuts after exercise. Give muscles a day off to recover between workouts. Get serious about pre-workout nutrition. Don't skip the stretching. Eat potassium-rich foods. Focus on quality sleep.

Get a massage.

**Rest & Relax** The most important thing for your cancer treatment and exercise recovery is to listen to the body. If you are feeling tired, sore or notice decreased performance you may need more recovery time or a break from exercise altogether. Pay attention, in most cases, the body will communicate what it needs, when it needs it. Listen and be kind to the body, and the body will be kind to you.

#### **Aging & Exercise Safety**

Regular physical activity helps you look and feel younger and stay independent longer. It also lowers your risk for a variety of conditions, including Alzheimer's and dementia, heart disease, diabetes, certain cancers, high blood pressure, and obesity. And the mood benefits of exercise can be just as great at 60 or 70 as they were at 20 or 30. Getting active is one of the healthiest decisions you can make as you age, but it's important to do it safely.

Starting or maintaining a regular exercise routine is a challenge at any age. You may not know where to begin, or perhaps you think you're too old or frail. These may seem like good reasons to take it easy as you age, however, they're even better reasons to get moving. Becoming more active can energize your mood, relieve stress, help you manage symptoms of illness and pain, and improve your overall sense of well-being. Staying active is what will keep us active in long run. Maintaining health, strength and flexibility is simpler than recovering them. Additionally, regular exercise can build strength and stamina, prevent loss of bone mass and improve balance.

## QUESTIONS TO **ASK BEFORE** JOINING A SUPPORT GROUP

Each type of support group has its own advantages and disadvantages. You may find that you prefer a structured, moderated group. Or meeting less formally with a small group of people. Some people may prefer online support groups.

> Is it geared toward a specific condition?

> Is the location convenient for regular attendance?

What is the meeting schedule?

Is there a facilitator or moderator?

Is a mental health expert involved with the group?



Is it confidential?

Does it have established ground rules?

What is a usual



meeting like?

Is it free, and if not, what are the fees?

Does it meet your cultural or ethnic needs?



## STARTING OR MAINTAINING A REGULAR exercise routine is a challenge at any age

You may not know where to begin, or perhaps you think you're too old or frail. These may seem like good reasons to take it easy as you age, however, they're even better reasons to get moving



LISTEN TO

THE BODY

**DO NOT** 

**OVER TRAIN** 

START SLOW AND BUILD

**STEADILY** 

**AVOID INJURY** 

& PAIN.

moving, boost your health and outlook, and improve how you age. Getting active is one of the healthiest decisions you can make as you age, but it's important to do it safely.

Get medical clearance from your healthcare team before starting an exercise program, especially if you have a preexisting condition. Ask if there are any activities you should avoid. Additionally, do not add supplements to your diet without consulting your physician.

Consider health concerns. Keep in mind how your ongoing health problems affect your workouts. For example, diabetics may need to adjust the timing of medication and meal plans when setting an exercise schedule. Cancer patients undergoing treatment might need to minimize or adjust their routine.

Listen to the body. Exercise should never hurt or make you feel badly. Stop exercising immediately and call your doctor if you feel dizzy or short of breath, develop chest pain or pressure, break out in a cold sweat, or experience pain. And put your routine on hold if a joint is red, swollen, or tender to the touch —the best way to cope with injuries is to avoid them in the first place. If you regularly experience pain or discomfort after exercising, try exercising for less time but more frequently throughout the day. If pain continues, consult with your physician.

Start slow and build up steadily. If you haven't been active in a while or are undergoing cancer treatment, build up your exercise program little by little. Try spacing workouts in ten-minute increments twice a day. Or try just one class each week. If you're concerned about falling or have an ongoing heart problem, start with easy chair exercises to slowly increase your fitness and confidence.

Do Not Over Train. Prevent injury and discomfort by warming up, cooling down, and keeping water handy. Excessive exercise or heavy training at every session or a lack of rest days will limit your fitness gains and could damage the body.

## **Stay Motivated**

It's easy to become discouraged when illness, injury, or changes in the weather interrupt routine. The good news is that starting an effective exercise routine isn't as unpleasant or difficult as it seems. Start by making the first few steps small, which will stimulate more action and build towards more. That's motivation. Motivation is a mental muscle that works a lot like your other muscles — the more you use it, the stronger it gets.

#### Here are a few good motivation muscle training tips to get you started:

Create REALISTIC expectations. Focus on what you can actually control. DON'T expect perfection. Focus on short term goals. Keep a journal or log. Reward yourself.

Benefiting from the rewards of exercise doesn't have to involve strenuous workouts, it's about adding more movement and activity to your life, even in small ways. No matter your age or physical condition, it's never too late to get your body Get support from friends & family.

Try to exercise, even when your regular routine is disrupted.

Even in the best circumstances, it can be difficult to get motivated to exercise, but it's much more difficult when feelings of fatigue set in. Research has shown that physical activity is very important, especially with cancer. It can improve patient function physically as well as their quality of life.

Always remember, too much rest can lead to loss of body function, muscle weakness, and reduced range of motion. So today, many cancer care teams are urging their patients to be as physically active as possible during cancer treatment. Many patients and caregivers are learning about the advantages of being physically active after treatment, too.

# 6. GLOSSARY

Active Surveillance or Watchful Waiting (**No Treatment**) A term used when a patient and/or physician monitors a potentially dangerous condition. A good example would be PSA monitoring of early stage A or B organ confined prostate cancer.

Adrenal Glands Two glands located above the kidneys that produce small amounts of the male hormone testosterone as well as other hormones.

**Antibody** A protein substance in the body produced in response to an antigen to provide immunity.

Antigen A biological substance, such as a vaccine or foreign protein, that produces an immunological response by producing antibodies.

**Asymptomatic** Without obvious signs or symptoms of disease. When cancer is in its early stages it may develop and grow without symptoms.

Benign Tumors Non-cancerous tumors that do no spread to other areas of the body.

**Biological Therapy** Also known as biotherapy or immunotherapy, is a new form of cancer treatment based on the knowledge and tools of modern molecular biology, immunology, and genetics.

**Biopsy** The removal and microscopic examination of a sample of tissue to ascertain if cancer is present. It is the most important procedure in diagnosing cancer. In the tradition "true cut" biopsy or spring loaded biopsy gun, a large hollow needle removes a core or plug of the tissue. In a fine needle aspiration, the tissue is aspirated, or sucked out, of the suspected area.

Bladder Catheterization Passage of a catheter into the urinary bladder through the urethra.

**Blood Count** Examination of a blood specimen in which the number of white blood cells (which protect against infection), red blood cells (which transports oxygen) and platelets (necessary for clotting blood) are determined.

**Bone Marrow** Soft tissue in bone cavities; produces blood cells.

**Chemotherapy** Treatment of cancer with certain chemicals that interfere with cell division not only of cancer cells, but all young and dividing cells of the body, such as blood cells. Chemotherapy alone may destroy immunity if given too long and too intensely. It is not usually curative for prostate cancer patients except in rare instances.

**Clinical Trial** A study conducted using patients, usually to evaluate a new treatment.

Cryosurgery or Cryoablation Minimally invasive computer-guided lethal freeze of all or part of the prostate using argon gas. Medicare-approved for primary and salvage treatment of localized prostate cancer. 89-92% success in 7-8 year studies.

Digital Rectal Examination (DRE) A procedure in which a physician inserts a finger in the rectum to examine the area as well as the prostate gland for signs of cancer.

**DNA** A nucleic acid found in cell nucleus that is the carrier of genetic information.

**Endocrinologist** A specialist of the endocrine glands and hormone systems of the body. i.e. pituitary gland, adrenal gland, testes.

**Enzyme** A protein that acts as a catalyst, increasing the rate at which chemical change occurs in the body.

**Gleason Score** A subjective method of measuring the differentiation of cells to classify tumors by their microscopic appearance and how aggressively cancer cells may multiply. This system divides prostate cancer into five histologic patterns ranging from 1-5. Patterns 1 and 2 represent well- differentiated tumors and are dealt with more easily; Gleason patterns 3 represents moderately well-differentiated tumor cells beginning to scatter; Gleason patterns 4 and 5 indicate poorly differentiated cells with the potential for fast growth. The total Gleason score is determined by adding a primary and secondary score pattern for each prostatic lesion i.e. 3+4=7. The most well-differentiated cancer cells would consist entirely of Gleason pattern 1 (primary

+ secondary + 1+1 or Gleason 2 ) and the most poorly differentiated cancer cells would have a 5+5 or total Gleason score of 10.

Hormone Therapy (HT) The use of medication or surgery to prevent cancer cells from getting the hormones needed to grow. In prostate cancer this means the hormone testosterone.

**Immunotherapy** Treatment by stimulation of the body's immune system.

**Impotence** Inability to have an erection suitable for intercourse. May be a result of an injury secondary to radiation therapy, surgical resection of the prostate, hormonal deprivation therapy, or other aspects of neurological, vascular or disease processes.

**Incontinence** Inability to hold urine in the bladder. May be a result of radiation therapy, surgical resection of the prostate, or other disease process.

**Lymph Nodes** Small bean-shaped structures scattered along the vessels of the lymphatic system. The nodes filter bacteria and cancer cells that may travel through the system.

Magnetic Resonance Imaging (MRI) A picture produced by a computer and a high powered magnet that shows a detailed x-ray type image of a particular body part or region that can detect if the tumor has penetrated the prostate gland and/or invaded the seminal vesicles. It can also be used to evaluate whether lymph nodes are enlarged.

#### Malignant Tumors Cancerous tumors.

**Metastasis** The spread of cancer cells from one part of the body to another by way of the lymph system, blood stream or direct extension.

Metastatic Work Up Includes bone scans, bone x-rays, chest x-rays, blood PSA tests and probably blood acid phosphatase and alkaline phosphatase.

Nerve Sparing Technique A surgical technique during a radial prostatectomy where one or both of the neurovascular bundles controlling erections are spared.

The utilization of this procedure is governed by the extent of the cancer.

**Oncologist** A medical doctor specializing in cancer.

**Oncology** The branch of medical science dealing with tumors.

**Pathologist** A doctor who specializes in the diagnosis of disease by studying cells and tissues removed from the body.

**Prostate Gland** A walnut-size gland that surrounds the neck of the bladder and approximately the first inch of the urethra. Its main function is to supply fluid for the sperm during ejaculation.

Prostate Specific Antigen (PSA) A blood test for the measurement of a substance produced by prostate gland cells. An elevated reading indicates an abnormal condition of the prostate gland, either benign or malignant requiring further investigation. The PSA is the most sensitive "marker" of the prostate cancer currently available and is used to monitor the progress of a patient undergoing treatment as well as after surgery or radiation therapy.

There are two PSA assays: The more commonly used is the Hybritech where a score of 0-4 is generally considered within the normal range. The other is called the Yang Pros - Check where a score of 0-2.5 is generally considered within the normal range. To convert from Hybritech to Yang Pros-Check you multiply your assay by .625. To convert from Yang Pros - Check to Hybritech you multiply your assay by 1.625.

**Protocol** The term used to describe an individual's treatment program.

Radiation Therapy (RT) Uses high energy rays to kill prostate cancer cells. Usually healthy cells are also affected. Like surgery, radiation therapy works best when the tumor is small and localized. There are two ways in which high frequency rays can be delivered: one by External Beam Radiation four or five times a week over six or seven weeks; the other by Interstitial Radiation Therapy also referred to as Brachytherapy, receiving rays from tiny radioactive seeds inserted directly into the prostate tumor. Most men are able to have sexual intercourse after interstitial radiation. Other forms of radiation are Proton Beam Irradiation which has high selectivity without damage to surrounding tissue and negligible morbidity; 3-D Directed Radiation which utilizes computer generated scans that provide the ability to confine the radiation selectively to the targeted area without peripheral involvement; and Neutron Therapy which is specialized radio therapy using atomic particles.

Radical Prostatectomy An operation to remove the entire prostate gland and seminal vesicles through the lower abdomen.

**Remission** Complete or partial disappearance of the signs and symptoms of disease in response to treatment. The period during which a disease is under control. A remission does not necessarily mean a cure.

**Staging** A medical term for the process of determining if a known cancer is still confined within the prostate where it is curable, or if it has spread outside of the prostate gland where it is probably not curable, but treatable. It is a system for classifying patients with malignant disease according to the extent and severity of disease, and thereby helping to determine the appropriate therapy.

There are 2 systems for staging Prostate Cancer. The Whitmore-Jewett ranges from A to D with substages for more precise definition. The Tumor Nodes Metastisis (TNM) staging system offers greater precision and ranges from T1 through the T's and M's as shown below:

**Testosterone** A male sex hormone produced by the testicles with a small amount produced by adrenal glands. It is associated with the activity and growth of the prostate gland and other sex organs.

**Ultrasound** A non-invasive imaging modality utilizing high frequency sound waves for visualizing tissue. Trancretal Ultrasound is becoming a more prevalent tool in the diagnosis and treatment of prostate cancer.

**Ureter** The tube that carries urine from each kidney to the bladder.

**Urethra** The tube that carries urine from the bladder and fluid from the prostate through the penis to the outside of the body. It is the first part of the urethra leading from the neck of the bladder, surrounded by the prostate gland and ends at the external sphincter muscle.

**Urologist** A doctor who specializes in diseases of the urinary and sex organs of humans.