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4th Edition

# PROSTATE CANCER

*A guide for patients and their families*

*Find  
strength  
in friendship*

Published in partnership with

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PROSTATE CANCER

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# Prostate Cancer Support Programs



**ZERO offers resources for  
all those impacted by prostate cancer.**

**ZERO360: Comprehensive Patient  
Support** ([zerocancer.org/zero360](http://zerocancer.org/zero360))  
1-844-244-1309 (Toll-Free)

ZERO360 is a free, comprehensive patient support service that helps patients navigate insurance, find resources to help pay for treatment and living expenses, connect with emotional support services, and ensure access to care. ZERO's experienced case managers are ready to help patients and their families through their personal prostate cancer journeys.

*"I was alone in my doctor's office when I first heard the words, 'You have prostate cancer.' I felt scared and confused. My life as I knew it was about to change. Contacting ZERO was the best thing I ever did; it changed my life! Each day spent with prostate cancer is a fight. I'm grateful to you for helping make sure a ZERO360 case manager was there to assist me every step of the way."*



– Rallie Settles,  
Patient

**Us TOO Support Groups** ([zerocancer.org/supportgroups](http://zerocancer.org/supportgroups))

A variety of peer-led virtual and in-person groups are available offering emotional support, resources, and education to empower those impacted by prostate cancer to make informed decisions on testing, treatment, and management of side effects.

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

A one-to-one peer support network where trained, volunteer MENtors have a wealth of insights to share based on their experiences.

**Online Support Services**

ZERO Connect ([facebook.com/groups/zeroconnect](https://facebook.com/groups/zeroconnect)) is a Facebook-based support group for participants to share stories, ask questions, and connect. An invite-only Facebook group also exists for Black men/caregivers (email [healthequity@zerocancer.org](mailto:healthequity@zerocancer.org) for information).

**Educational Resources** ([zerocancer.org](http://zerocancer.org))

ZERO offers a variety of educational resources and events for prostate cancer awareness, screening, treatment, and side effects.

Visit ZERO Prostate Cancer to get help at  
**ZEROCANCER.ORG**



# PROSTATE CANCER

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# Education is vital with a prostate cancer diagnosis

**A**dvances in care are offering more options to men who have prostate cancer. When found early, prostate cancer has one of the highest survival rates of any cancer. For advanced stages, a variety of treatments are available.

## THE PROSTATE GLAND

The prostate is a walnut-sized gland located behind the base of the penis, situated under the bladder and in front of the rectum (see Figure 1). It wraps around the urethra, the tube-like channel that carries urine and semen through the penis. The prostate makes seminal fluid, the liquid in semen that protects, supports and helps transport sperm out of the body.

As men age, their prostate tends to enlarge. This may result in symptoms such as problems with urination or sexual function, but an enlarged prostate does not mean you have cancer. Such enlargement with age is called benign prostatic hypertrophy (BPH). One of the symptoms is that the urethra becomes blocked, making it difficult to urinate.

Although blockage of urine flow may occur because of prostate cancer, such symptoms are far more likely to be caused by BPH, which is not associated with a greater risk of developing prostate cancer.

It is important to be in tune with your body and be willing to talk with your medical team about any symptoms to determine what is causing them.

## ABOUT PROSTATE CANCER

Cancer begins when healthy cells in the prostate change and grow out of control, forming a tumor.

Early-stage prostate cancer means the cancer is contained within the prostate and has not spread outside of the gland. Advanced stage prostate cancer has metastasized, or

spread, beyond the prostate to other areas of the body. Metastasis occurs when cancer cells travel throughout the body via the bloodstream or the lymphatic system. The lymphatic system is the network of lymph nodes and vessels that are critical for your body to fight infections. Disease-fighting cells such as lymphocytes are carried in the clear fluid called lymph, which circulates throughout the body. Lymph nodes help filter the lymph fluid to remove germs and fight disease. They are found all over the body.

## SEEK A SECOND OPINION

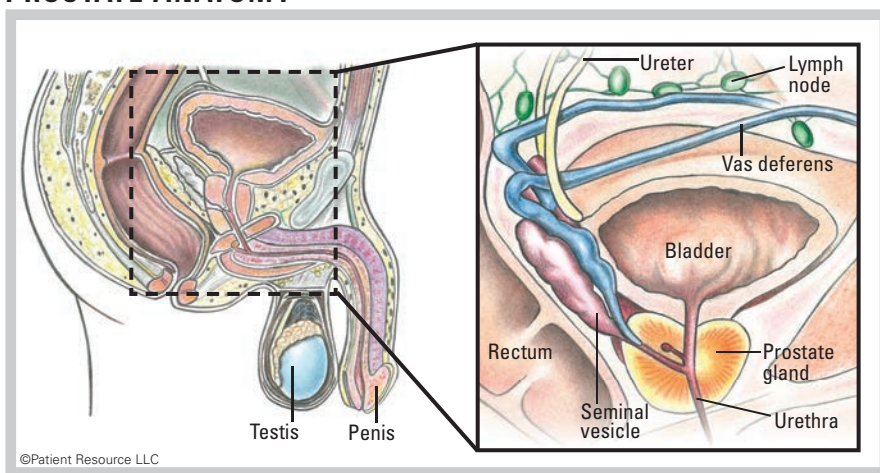
Once you receive a prostate cancer diagnosis, consider getting a second opinion. Your care decisions may affect many areas of your life. You deserve to explore all your options.

Your urologist may have made the initial diagnosis, and while you may be very confident with that care team, you could benefit from talking with specialists who have extensive experience treating your type of prostate cancer. These may include a pathologist, medical oncologist, radiation oncologist or surgeon.

Getting a second opinion can be beneficial in the following situations:

- There is uncertainty surrounding your diagnosis.
- You want to feel more confident that you have chosen the best treatment plan.
- You would like to learn about other treatment strategies.
- You are not comfortable with your medical team's communication style or with the treatment options you have been given.
- You have a rare or advanced form of prostate cancer.
- Your insurance company requires one. ■

FIGURE 1  
PROSTATE ANATOMY



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## TERMS TO KNOW A cancer diagnosis comes with new vocabulary. It may help to familiarize yourself with some common terms.

**First-line therapy** is the first treatment given for a disease. It is often composed of a combination of treatments, such as surgery followed by hormone therapy, chemotherapy and/or radiation.

**Local therapy** is treatment that is directed to a specific organ or limited area of the body. For prostate cancer, local treatments include surgery and radiation therapy.

**Metastasis** is the spread of cancer cells from the place where they first formed to

another part of the body.

**Oncologist** is a doctor who has special training in diagnosing and treating cancer.

**Palliative care** is given to improve the quality of life and help reduce pain in people who have a serious or life-threatening disease, such as cancer.

**Recurrence** is when cancer comes back, usually after a period of time during which it could not be detected.

**Standard of care** is treatment that is accepted by medical experts as a proper treatment for a certain type of disease and that is widely used by health care professionals.

**Systemic therapy** uses medication that travels through the bloodstream, reaching and affecting cells all over the body. Medications may be given intravenously (through an IV) into a vein or swallowed orally (a pill or capsule).

# Key tests used to determine the extent of the cancer

**P**rostate cancers are most often first discovered as a result of a blood test for prostate-specific antigen (PSA), a protein found in the blood of men and produced primarily by normal and malignant prostate glands. Your doctor may order this blood test because a prostate problem is suspected or simply as a routine screening test. Once your doctor suspects you may have prostate cancer, additional tests will be needed to confirm a diagnosis.

Your doctor may perform any of the following tests. Some may also be used for monitoring once treatment begins.

## PHYSICAL EXAM

A **digital rectal exam (DRE)** is a test to screen for prostate cancer and to determine the size of the tumor. The doctor will insert a lubricated, gloved finger into your rectum and feel for any abnormalities in the prostate.

## BLOOD TESTS

**Prostate-specific antigen (PSA)** is a common biomarker test performed to look for prostate cancer. Biomarkers are substances in blood, body fluids or tissues that may indicate a condition or disease, such as cancer. Some PSA enters the bloodstream and can be measured in a small sample of blood.

Generally, higher PSA levels indicate a greater likelihood that prostate cancer cells are present. But infection, inflammation, enlargement or other injuries to the prostate can also increase a man's PSA level. The U.S. Food and Drug Administration originally

approved the test to be used in combination with a digital rectal exam (DRE), and they are often used together for screening and diagnosing prostate cancer.

A man's PSA level may increase with age. It is important to be tested regularly so your doctor can compare these levels over time and watch for an increase, which may indicate a need for further evaluation.

Other tests may be used along with the PSA to better determine whether you have cancer and to avoid unnecessary biopsies:

- **PSA density (PSAD)** may be used in men with larger prostate glands. PSAD attempts to consider the fact that benign enlargement of the prostate in and of itself may increase the PSA level. A higher PSAD level may indicate a greater likelihood of cancer. It is calculated by dividing the PSA by the size of the prostate measured by ultrasound or MRI.
- **PSA velocity** measures how fast PSA levels change over time. A high PSA velocity (i.e., a more rapidly increasing PSA) may indicate prostate cancer and may help

find fast-growing prostate cancers.

- **PSA doubling time** is the time it takes for the PSA level to double. It indicates how fast the cancer is growing, spread of the cancer beyond the prostate, or both, and it may be used to determine your risk for a recurrence if you have already been treated for prostate cancer.
- **Percent-free PSA** is a type of PSA test that measures the proportion of the total PSA that is circulating "freely" in the blood (not bound to other blood proteins). It is compared to the amount of PSA attached to other proteins. Men with benign prostatic hypertrophy (BPH) have higher amounts of free PSA.
- **Prostate Health Index (PHI)** measures PSA, free PSA and proPSA and uses a formula to predict the presence of prostate cancer in men with an elevated PSA level.
- **4Kscore Test** measures PSA, free PSA, intact PSA and human kallikrein 2 (hK2) in a blood sample and combines these results with age, DRE and whether a man had a previous negative biopsy into an algorithm to predict the likelihood that a biopsy would show a high-grade cancer.

## URINE TESTS

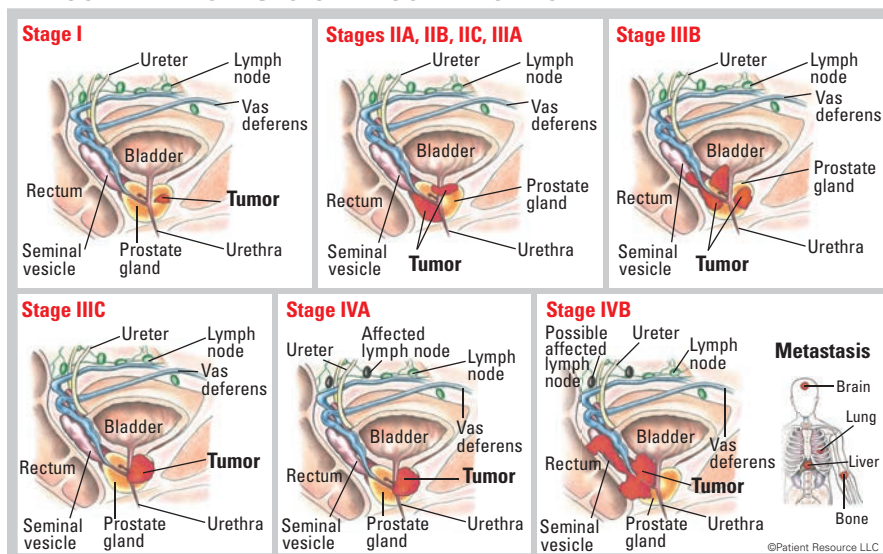
Some biomarkers can be tested for in urine. The PCA3 test measures the level of the prostate cancer antigen 3 (PCA3) in the urine. This test may be done with PSA testing to determine whether a repeat biopsy is necessary in men who have had negative results on previous biopsies.

## BIOPSIES

A biopsy is the only way to definitively diagnose prostate cancer. Multiple tissue samples (typically 12 to 14) are usually collected to be examined under a microscope.

- **Core needle biopsy** is the most commonly used test for detecting the presence of cancer in the prostate.
- **Transrectal ultrasound (TRUS)-guided biopsy** uses sound waves to visualize the prostate and evaluate for cancer and other conditions. The ultrasound image is also used by the doctor to guide needles to the correct areas during the biopsy.

## ILLUSTRATED STAGES OF PROSTATE CANCER



Continued on page 4



- o **Transperineal ultrasound-guided biopsy** removes tissue with a thin needle that is inserted through the skin between the scrotum and rectum and into the prostate.
- **MRI-ultrasound fusion biopsy** fuses, or combines, detailed MRI images with live, real-time ultrasound images of the prostate. An MRI is done first. At another appointment, an ultrasound of the prostate is performed. Fusion software combines the images from both tests and gives the doctor a detailed three-dimensional ultrasound/MRI view to help guide the biopsy needles more precisely to areas suspicious for cancer.
- **Pelvic lymphadenectomy** is a surgical procedure to remove lymph nodes in the pelvis to see whether they contain cancer. This procedure is important to determine the cancer's stage. Lymph node removal may be done at the same time surgical removal of the prostate is performed.
- **Seminal vesicle biopsy** uses a needle to remove a sample of tissue from the seminal vesicles, imaged by ultrasound, to check for spread of the cancer.

## IMAGING TESTS

**Transrectal ultrasound (TRUS)** uses sound waves to visualize organs. This imaging test may be used to find possible areas of cancer, assist with a biopsy, measure the size of the prostate gland and guide some forms of treatment. During this test, the technician

will insert a lubricated transducer (a small instrument that emits sound waves) into the rectum. As the sound waves reach the prostate and create echoes, images of the prostate will appear on the monitor.

**Magnetic resonance imaging (MRI)** uses magnetic fields to visualize internal organs in the body. The MRI may be particularly helpful in showing a detailed view of the prostate.

**Multiparametric MRI (mpMRI)** may be used to find possible areas of cancer in the prostate. mpMRI employs injection of contrast material into a vein to provide a more detailed picture of the prostate. This procedure provides more sensitive information regarding a cancer and allows the physician to gain some information about the aggressiveness of the tumor, such as how quickly it may grow and the risk the cancer has grown outside the prostate or spread to other organs.

A **bone scan** may be performed to determine whether cancer has spread to the bones.

**Computed tomography (CT)** is primarily performed to look for the spread of cancer to lymph nodes and other organs but is not especially helpful at showing details inside the prostate.

**Positron emission tomography (PET)** involves intravenous administration of a tiny

dose of radioactivity to identify whether the cancer has spread. A new version of PET, the PSMA PET, attaches to prostate-specific membrane antigen (PSMA), a protein found in prostate cancer cells.

Such a scan is called ProstaScint scan and it detects the presence of PSMA on the surface of prostate cancer cells using an antibody carrying a radioactive molecule that can be detected by single photon emission computed tomography (SPECT).

## STAGING AND GRADING PROSTATE CANCER

Test results are used to stage the cancer. Then the cancer is given a grade, which is how abnormal the cancer cells look under a microscope.

The TNM system from the American Joint Committee on Cancer (AJCC) is the staging system used to classify and stage prostate cancer. The tumor (T) is categorized by its size, including how much of the prostate is occupied by cancer and whether it has spread to adjacent structures such as the seminal vesicles, rectum, bladder and/or pelvic wall; whether cancer has affected nearby lymph nodes (N); and whether the cancer has metastasized (M), or spread, to other parts of the body.

Prostate cancers are graded from 3 to 5 using the Gleason scoring system, based on how different the cancerous cells appear from normal, healthy cells. A pathologist examines biopsied tissue containing cancer in areas that make up the largest portion of cancer cells, assigning a Gleason score to cancer cells in this area. Then the Gleason score of the second largest area of cancer is determined. The final Gleason score is the sum of these two numbers expressed as the total and component scores (such as 4+3=7). The higher the Gleason grade, the more aggressive the tumor is and the more likely it is to spread. ■

## AJCC TNM SYSTEM FOR CLASSIFYING PROSTATE CANCER

Classification	Definition
<b>Tumor (T)</b>	
<b>TX</b>	Primary tumor cannot be assessed.
<b>T0</b>	No evidence of primary tumor.
<b>T1</b>	Clinically inapparent (produces no signs or symptoms) tumor that is not palpable (noticeable by touch).
<b>T1a</b>	Tumor incidental histologic finding in 5 percent or less of tissue resected.
<b>T1b</b>	Tumor incidental histologic finding in more than 5 percent of tissue resected.
<b>T1c</b>	Tumor identified by needle biopsy found in one or both sides, but not palpable (noticeable by touch).
<b>T2</b>	Tumor is palpable (noticeable by touch) and confined within prostate.
<b>T2a</b>	Tumor involves one-half of one side (one prostate lobe) or less.
<b>T2b</b>	Tumor involves more than one-half of one side (one prostate lobe) but not both sides (both lobes).
<b>T2c</b>	Tumor involves both sides (prostate lobes).
<b>T3</b>	Extraprostatic tumor (tumor extends beyond the prostate gland) that is not fixed or does not invade adjacent structures.
<b>T3a</b>	Extraprostatic extension (tumor extends beyond the prostate gland) (unilateral or bilateral).
<b>T3b</b>	Tumor invades seminal vesicle(s) (gland on each side of the bladder).
<b>T4</b>	Tumor is fixed or invades adjacent structures other than seminal vesicles such as external sphincter, rectum, bladder, levator muscles and/or pelvic wall.
<b>Node (N)</b>	
<b>NX</b>	Regional nodes were not assessed.
<b>N0</b>	No positive regional nodes.
<b>N1</b>	Metastases in regional node(s).
<b>Metastasis (M)</b>	
<b>M0</b>	No distant metastasis.
<b>M1</b>	Distant metastasis.
<b>M1a</b>	Nonregional lymph node(s).
<b>M1b</b>	Bone(s).
<b>M1c</b>	Other site(s) with or without bone disease.

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

## STAGES OF PROSTATE CANCER

Group/stage	T	N	M	Grade group	Prostate-specific antigen (PSA) level
<b>I</b>	T1a-c	N0	M0	1	Less than 10
	T2a	N0	M0	1	Less than 10
<b>IIA</b>	T1a-c	N0	M0	1	Greater than or equal to 10, but less than 20
	T2a	N0	M0	1	Greater than or equal to 10, but less than 20
	T2b-c	N0	M0	1	Less than 20
<b>IIB</b>	T1-2	N0	M0	2	Less than 20
<b>IIC</b>	T1-2	N0	M0	3	Less than 20
	T1-2	N0	M0	4	Less than 20
<b>IIIA</b>	T1-2	N0	M0	1-4	Greater than or equal to 20
<b>IIIB</b>	T3-4	N0	M0	1-4	Any level
<b>IIIC</b>	Any T	N0	M0	5	Any level
<b>IVA</b>	Any T	N1	M0	Any grade	Any level
<b>IVB</b>	Any T	Any N	M1	Any grade	Any level

# Learn how specialized testing may help guide treatment decisions

**C**ancer forms when one or more normal genes change, or mutate, and this leads to disruption of the controls on growth and mobility that maintain structure and function of normal cells. Cancer is ultimately a disease of our genes, which are pieces of DNA — the information plan for the growth and control of cells. Because several genes have been associated with the development of prostate cancer, one key to understanding and treating it is through genomic testing.

Mutations are generally described as one of two types. They may be inherited from your parents or occur during a person's lifetime from environmental factors, such as tobacco use, ultraviolet radiation, viruses, age or random mistakes in replication of DNA. Your doctor may use specialized testing known as genomic testing (molecular testing) or genetic testing to determine whether you have mutations — either in your normal cells (this is called germline testing) or in your cancer cells.

## GENOMIC TESTING

This type of testing involves testing for mutations in the DNA of your cancer cells. Such testing is typically performed as part of the evaluation process to detect biomarkers, which are substances such as genes or molecules that can be measured in the blood, urine or other body fluids or tissues. Such markers may provide information that helps your doctor make a diagnosis or plan treatment based on the likely aggressiveness of your cancer, which is the likelihood that your cancer will be resistant to treatment or spread (metastasize) to other areas of the body. Such tests help determine whether your cancer is at high or low risk of spread or return despite standard treatment, and this may impact timing and type of treatments recommended. These tests are performed on a sample of cancerous tissue taken from a biopsy or surgical specimen.

Genomic testing may also be used to identify whether your cancer has mutations for which targeted therapies are available. Your doctor may look for mutations in the *BRCA1*, *BRCA2* and other genes.

## GENETIC TESTING

Genetics is the study of genes and the passing of genetic information and traits from

parents to children (heredity). Some cases of prostate cancer are inherited, and abnormalities influencing such inheritance can be detected in normal cells (blood or cheek swab specimen). Finding mutations in some genes may indicate an increased risk of developing cancer. Just because someone tests positive for a genetic mutation does not mean they will develop cancer. It just means the risk is higher and additional screening may be needed.

Prostate cancer can run in families. If you have a family history of a particular type of cancer, you may consider genetic testing to find out whether you carry the gene or genes associated with familial risk of cancer. Some of the inherited mutated genes that have been associated with prostate cancer include:

- Hereditary Breast and Ovarian Cancer (HBOC) Syndrome associated with inherited mutations in *BRCA1* and *BRCA2* genes
- *PALB2*, *RAD51D*, *RNASEL* (formerly *HPC1*) and *HOXB13* gene mutations
- *ATM* and *CHEK2* mutations

- Mutations in the *MLHL*, *MSH2*, *MSH6*, *PMS2* and *EPCAM* genes, which cause Lynch Syndrome (hereditary nonpolyposis colorectal cancer)

In addition, characteristics in either you, or your family, history may increase the risk of familial cancer, such as:

- Family history of breast, colon, ovarian, pancreatic or prostate cancer
- An initial diagnosis of high-risk, regional or metastatic prostate cancer
- Ashkenazi Jewish ancestry
- Any other cancer diagnosis

## KNOWING YOUR FAMILY HEALTH HISTORY

Because genetic mutations can be passed down through families, knowing the health history of your family could offer valuable insights. Preventing or detecting a cancer early offers the best chance of a successful treatment outcome. This information could help your family members be screened and monitored closely if they have a gene mutation associated with cancer.

Interpreting the results of genetic testing can be challenging, so talking with a genetic counselor is recommended. Special training enables a genetic counselor to guide you and your family members before and after you have genetic testing. Ask a member of your health care team for a referral. ■

## GENE MUTATIONS

**Genes can mutate in a variety of ways that can increase a person's risk of developing cancer. Some mutations that can occur in genes include the following.**

**Gene amplification:** An increase in the number of copies of a gene, which is common in cancer cells. Some amplified genes may cause cancer cells to grow or become resistant to anti-cancer drugs.

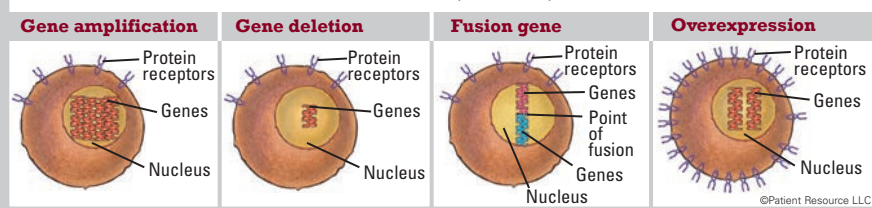
**Gene deletion:** The loss of all or part of a gene.

**Fusion gene:** A gene made by joining parts of two different genes. Fusion genes, and the fusion proteins that come from them, may be made in the body when part of the DNA from one

chromosome moves to another chromosome. Fusion proteins produced by this change may lead to the development of some types of cancer.

**Overexpression:** Too many copies of a protein or other substance, which may play a role in cancer development.

**Rearrangement:** A mutation that occurs in chromosomes where portions of the chromosome are not in order, which creates a new gene (not shown).



# Partner with your doctor to make more informed decisions

**U**nderstanding the options available to treat your prostate cancer is essential. Work closely with your medical team to learn about your choices, and have frank and honest discussions about each option and potential side effects. Learn as much as you can so you can understand your treatment plan.

Several types of prostate cancer treatment are available. To determine the treatment options that are the most appropriate for you, your doctor will consider the stage and grade of disease, and whether it has metastasized (spread), your age and overall health, results of risk assessments, predictive tests and more.

Your input at this time is important. Share your expectations for life during and after treatment, and ask about side effects, such as sexual function, fertility, and bladder and bowel control. Find out whether any are permanent or whether functionality can return. Although this is a delicate topic, do not be embarrassed. Your medical team is made up of highly skilled and compassionate professionals who are trained to help you through diagnosis and treatment.

## TYPES OF TREATMENT

Your doctor may recommend that you forego active treatment for the time being because treatment is not deemed necessary. If your cancer has features that indicate that it will be slow growing and unlikely to spread, treatment may be delayed or deferred. This offers the benefit of delaying side effects

that accompany treatment. This may be an option when the cancer is slow growing, for much older men who are not experiencing symptoms, for men who have complicating illnesses that make therapy risky or for men with a low stage of cancer.

**Watchful waiting** enables your doctor to closely monitor your condition. Treatment may be given to minimize symptoms.

**Active surveillance** delays active treatment until test results from a digital rectal exam, PSA test, transrectal ultrasound (TRUS) or transrectal needle biopsy indicate it is time to treat. Active surveillance entails regular testing (such as PSA, DRE, TRUS or biopsy).

Your treatment plan may include one of a combination of the following local and systemic therapies.

**Surgery** may be used alone or with another therapy.

A **radical prostatectomy** removes the entire prostate, surrounding tissues and the semi-

nal vesicles. Pelvic lymph nodes may also be removed. This surgery can be performed as open surgery, in which the prostate is removed through one large incision that can be from the belly button to the base of the penis (radical retropubic prostatectomy) or in the area between the scrotum and anus (radical perineal prostatectomy).

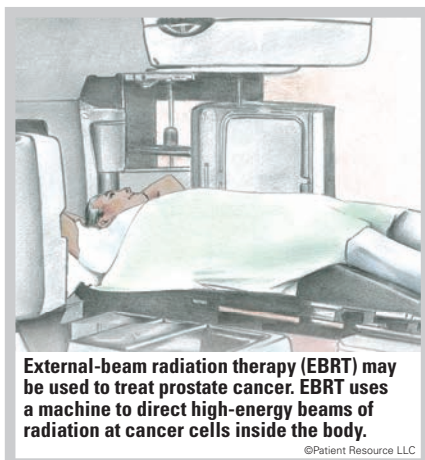
Minimally invasive surgery involves small incisions, robotic arms and an endoscope (robot-assisted radical prostatectomy). Minimally invasive surgery tends to result in shorter hospital stays, less blood loss, fewer surgical complications and a faster recovery time. The side effects, including erectile dysfunction and incontinence, are about the same with both types of surgery.

An **orchiectomy** surgically removes both testicles. It is a surgical form of hormone therapy used to reduce testosterone levels. Although not common, orchiectomy can generally be used for advanced prostate cancer that has spread.

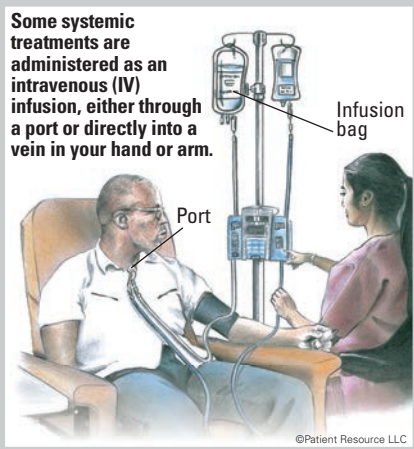
**Transurethral resection of the prostate (TURP)** is a procedure designed to relieve symptoms caused by a tumor, such as a urinary blockage. TURP is not designed to cure the cancer but only to relieve obstruction to voiding.

**Radiation therapy** may be given in an attempt to cure the cancer or after surgery to help prevent recurrence.

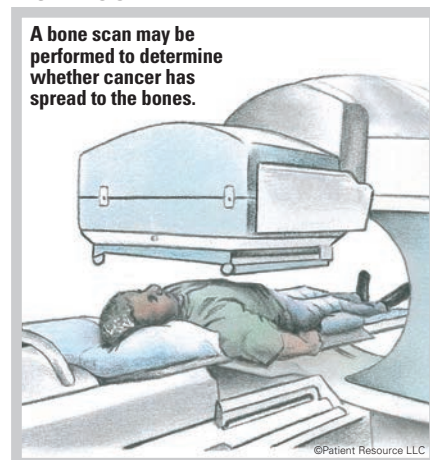
## FIGURE 1 RADIATION THERAPY



## FIGURE 2 DRUG THERAPY



## FIGURE 3 BONE SCAN





*External-beam radiation therapy (EBRT)* involves a large machine that aims radiation at the prostate and surrounding tissues (see Figure 1). High doses of radiation are focused on the cancer only, sparing healthy tissue from damage. Types of EBRT that may be used include the following:

- Stereotactic body radiation therapy (SBRT) uses high-energy radiation beams to treat cancer in fewer treatments.
- Three-dimensional conformal radiation therapy (3D-CRT) combines computed tomography (CT) images and computer software to aim beams that match the shape of the tumor.
- Intensity-modulated radiation therapy (IMRT) uses small beams of different strengths to match the shape of the tumor in the prostate and surrounding tissue.
- Proton beam radiation therapy uses streams of protons to kill tumor cells.
- Image-guided radiation therapy (IGRT) uses a computer to create a picture of the tumor that helps guide the radiation beams to ensure they target the same spot every time. It can be used with the other types of radiation.

*Brachytherapy*, also called internal radiation therapy, involves placing tiny radioactive “seeds,” or needles, directly into the prostate. Radiation may be delivered at a high-dose rate (over several hours) with needles implanted and removed a short time later or at a low-dose rate with small radioactive seeds that are permanently implanted. Combined with EBRT, it can also be used as a boost to treat intermediate or high-risk cancers.

*Radiopharmaceuticals* use a radioactive substance to treat cancer. One type is alpha emitter radiation therapy, which uses radiopharmaceuticals that are administered into the vein and travel throughout the bloodstream, delivering radiation to suppress cancer that has spread to the bones.

*High-intensity focused ultrasound (HIFU)* is a relatively new type of less-invasive treatment that uses high-energy sound waves to create heat to kill cancer cells. You are encouraged to find an expert in HIFU if you are considering it in your treatment plan.

**Drug therapy** is systemic therapy that may be used to treat prostate cancer. Given intravenously through a vein or orally, it may be used alone or in combination (see Figure 2).

*Hormone therapy* adds, blocks or removes hormones. It is often used in combination with other treatments.

Androgens are male hormones. The main male androgen is testosterone, and it helps prostate cancer grow. Therefore, reducing the amount of testosterone in the body can shrink the tumor or slow its growth.

A type of hormone therapy called androgen-deprivation therapy (ADT) may slow tumor growth by preventing the body from producing androgens or by blocking the effect the androgens have on the tumor.

Given as injections or orally, luteinizing hormone-releasing hormone (LHRH) agonists and LHRH antagonists cause the testicles to stop making testosterone, a form of medical castration. Anti-androgens and androgen synthesis blockers antagonize the effects of testosterone or reduce its production from areas of the body other than the testicles. They are available as oral medications.

Orchiectomy, a surgery that removes both testicles to reduce testosterone levels, and subcapsular orchiectomy, which only removes the tissue that makes testosterone but not the covering of the testicles, are also forms of hormone therapy.

*Chemotherapy* uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. It also affects healthy cells (see *Supportive Care*, page 10). To treat prostate cancer, it may be given intravenously (IV) through a small tube inserted into a vein or port, or taken orally as a pill.

*Targeted therapy*, also called molecular therapy, uses drugs to target specific biomarkers found as a result of genomic testing that identifies genes, proteins or other factors that support the tumor. After considering the test results, your doctor will determine the most appropriate treatment for you. Some targeted therapy drugs are oral medications given in pill form, and others may be given intravenously by a needle inserted into a vein.

*Immunotherapy* is a type of therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection and other diseases.

Two forms of immunotherapy are approved to treat advanced prostate cancer. One is a vaccine that involves the collection of white blood cells, which are modified in a lab to recognize prostate cancer cells and

then infused back into the body to find and destroy the cancer. Another is a monoclonal antibody that utilizes the body's ability to recognize and target cancer cells that have certain biomarkers.

*Bone-modifying (strengthening) therapy* uses drugs such as bisphosphonates to strengthen bones, slow or reverse bone loss, and may help relieve bone pain. This may also reduce the risk of bone fractures.

Bone-modifying therapy may be recommended when cancer metastasizes (spreads) to the bone or if a man is receiving androgen-deprivation therapy (ADT), as ADT increases the risk of osteoporosis, a bone condition that can be caused or worsened by hormone therapy.

Your doctor may order a bone scan at diagnosis as well as during treatment to monitor bone health (see Figure 3). Damage to the jaw, a condition known as osteonecrosis of the jaw, is a serious side effect of treatment with bisphosphonates. Involve your dentist before beginning therapy if bisphosphonates are part of your treatment plan.

## MEDICATION ADHERENCE

You may have many different medications in your treatment plan, and some of them, such as oral medications, can be taken at home. As such, you must remember that managing your cancer medications is important.

Most cancer therapies are designed to maintain a specific level of drugs in your system for a certain time based on your cancer type and stage, your overall health, previous therapies and other factors. You will get the most benefit from your medications if you take your medications exactly as your doctor intends.

Stay on track with medication adherence by doing the following:

- Talk with your pharmacist or another member of your health care team to ensure you understand how to take your medications.
- Be open and honest about any barriers you have for taking your medications, such as cost or side effects.
- Get in the habit of taking your medications at the same time every day.
- Use a pill organizer so you know whether you have taken a dose.
- Set reminders using apps, calendars, notes or timers.

*Continued on page 8*

### PSA PERSISTENCE AND RECURRENCE

Sometimes, even after treatment ends, cancer returns. The recurrence of prostate cancer can be detected in different ways. One indication that recurrence has happened is a measurable and increasing PSA blood level. If the PSA does not fall to or near zero after treatment, it is called PSA persistence. When the PSA level falls close to zero but subsequently rises, it is referred to as recurrence.

Recurrence or persistence of PSA will usually prompt your doctor to repeat other tests, such as a bone scan, CT or MRI. The management of recurrent or persistent PSA will depend on other types of therapy you have received and whether evidence of spread of the cancer to other organs is detected. Each of these conditions is treated uniquely. Discuss the potential treatment options with your doctor.

### CLINICAL TRIALS

Clinical trials are medical research studies that evaluate treatments that involve new drugs, drug combinations, new radiation and surgical techniques, and other strategies to learn how they compare to existing treatments.

Consider discussing clinical trials and whether you may qualify for one with your doctor.

#### Myths vs Facts

Clinical trials are often misunderstood. Such misunderstanding may prevent people from participating in them, and this slows down progress in cancer research.

Following are some common myths and the facts that address them.

**Myth:** *Once the clinical trial begins, you must remain in it for the duration of the trial.*

**Fact:** Taking part in a clinical trial is voluntary, and you can leave the study at any time.

**Myth:** *Clinical trials are only available to people who have exhausted all other treatment options.*

**Fact:** Trials are available for all stages of cancer. Any time you or a loved one needs treatment for cancer, clinical trials might be an option to consider. Ask your doctor about clinical trials that might be an option for you.



**Myth:** *Clinical trials are held only in large cancer centers in big cities.*

**Fact:** Cancer clinical trials take place in doctors' offices, clinics, cancer centers, veterans' hospitals and other locations in cities and towns across the United States and around the world. However, you are not limited to the trials that are near you. If you choose to travel for a clinical trial but are concerned about the expenses of travel and lodging, resources may be available to help you cover the costs. ■

## » Explaining castration-resistant prostate cancer (CRPC)

**Prostate cancer that continues to grow** even when the amount of testosterone in the body is reduced to very low levels by medical or surgical treatment is called castration-resistant prostate cancer (CRPC).

CRPC is defined by a rising PSA level and/or worsening symptoms and/or growing cancer verified by scans. If the cancer has not spread to other parts of the body, it is known as non-metastatic CRPC. CRPC that is no longer stopped by low testosterone levels and has spread to other parts of the body is called metastatic castration-resistant prostate cancer. It is also defined by a rising PSA level and/or worsening symptoms and/or growing cancer verified by scans.

If you develop CRPC, talk with your doctor about your goals of treatment. Discuss the potential side effects of a new treatment strategy and how that fits in with your life.

Treatment for non-metastatic CRPC includes continuing to lower testosterone levels with drug therapy, generally hormone therapy or chemotherapy. The type of drug used will depend on your previous treatments and the risk of the cancer metastasizing (spreading). Surgery, such as orchiectomy to permanently stop the production of testosterone, may also be an option.

Various strategies to treat metastatic CRPC may include drug therapies, such as hormone therapy, targeted therapy, immunotherapy and radiopharmaceuticals. Bone-modifying (strengthening) drugs may also be prescribed. This may be a good time to talk with your doctor about participating in a clinical trial.



Talk with your doctor about a regular follow-up schedule to help monitor your condition. Non-metastatic CRPC will be monitored using PSA testing and/or imaging tests, such as bone scans, CT or MRI, to detect spread as soon as it occurs. The frequency of these tests will depend on the risk of metastasis. For metastatic CRPC, regularly scheduled PSA testing is common, and imaging tests will be performed when symptoms or signs indicate that the cancer is spreading.

## CLINICAL TRIALS GLOSSARY

**Arm:** A group or subgroup of participants in a clinical trial that receives a specific intervention/treatment, or no intervention, according to the trial's protocol.

**Exclusion criteria:** A type of eligibility criteria. These are reasons that a person is not allowed to participate in a clinical study.

**Expanded access:** A way for patients with serious diseases or conditions who cannot participate in a clinical trial to gain access to a medical product that has not been approved by the U.S. Food and Drug Administration (FDA). Also called compassionate use.

**Inclusion criteria:** A type of eligibility criteria. These are the reasons that a person is allowed to participate in a clinical study.

**Informed consent:** A process used by researchers to communicate to potential and enrolled participants the risks and potential benefits of participating.

**Intervention/treatment:** A process or action that is the focus of a clinical study.

Interventions and treatments include drugs, medical devices, procedures, vaccines and other products that are either investigational or already available. They can also include noninvasive approaches, such as education or modifying diet and exercise.

**Investigator:** A researcher involved in a clinical study. Related terms include site principal investigator, site sub-investigator, study chair, study director and study principal investigator.

**NCT number:** The unique identification code given to each clinical study upon registration at ClinicalTrials.gov. The format is NCT followed by an 8-digit number (for example, NCT00000419).

**Phase:** The stage of a clinical trial studying a drug or biological product, based on definitions developed by the U.S. Food and

Drug Administration (FDA).

**Primary outcome measure:** In a clinical study's protocol, the planned outcome measure that is most important for evaluating the effect of an intervention/treatment. Most clinical studies have one primary outcome measure, but some have more than one.

**Primary purpose:** The main reason for the clinical trial. The types of primary purpose are treatment, prevention, diagnostic, supportive care, screening, health services research, basic science and other.

**Principal investigator (PI):** The person who is responsible for the scientific and technical direction of the entire clinical study.

**Protocol:** The written description of a clinical study. It includes the study's objectives, design and methods. It may also include relevant scientific background and statistical information.

**Sponsor:** The organization or person who initiates the study and who has authority and control over the study.

**Study completion date:** The date on which the last participant in a clinical study was examined or received an intervention or treatment to collect final data for the primary outcome measure(s), secondary outcome measure(s) and adverse events (that is, the last participant's last visit).

**U.S. Food and Drug Administration (FDA):** An agency within the U.S. Department of Health and Human Services. The FDA is responsible for protecting the public health by making sure that human and veterinary drugs, vaccines and other biological products and medical devices as well as the nation's food supply, cosmetics, dietary supplements and products that give off radiation are safe, effective and secure. ■

## Reimbursement & Patient Assistance Programs



- ▶ **Astellas Pharma Support Solutions** [astellaspharmasuportsolutions.com/patient](http://astellaspharmasuportsolutions.com/patient), 800-477-6472
- ▶ **AstraZeneca Access 360** [myaccess360.com/patient](http://myaccess360.com/patient), 844-275-2360
- ▶ **AstraZeneca Prescription Savings Program (AZ&ME)** [azandmeapp.com](http://azandmeapp.com), 800-292-6363
- ▶ **Bayer US Patient Assistance Foundation** [patientassistance.bayer.us](http://patientassistance.bayer.us), 866-228-7723
- ▶ **ClovisCares** [www.mycloviscares.com](http://www.mycloviscares.com), 844-779-7707
- ▶ **Janssen CarePath** [www.janssencarepath.com](http://www.janssencarepath.com), 877-227-3728
- ▶ **Merck Access Program** [www.merckaccessprogram.com/hcc/](http://www.merckaccessprogram.com/hcc/)
- ▶ **Merck Patient Assistance Program** [www.merckhelps.com](http://www.merckhelps.com), 800-727-5400
- ▶ **Novartis Oncology Universal Co-pay Program** [copay.novartisoncology.com](http://copay.novartisoncology.com), 877-577-7756
- ▶ **Novartis Patient Assistance NOW Oncology (PANO)** [patient.novartisoncology.com/financial-assistance/pano](http://patient.novartisoncology.com/financial-assistance/pano), 800-282-7630
- ▶ **Pfizer Oncology Together** [www.pfizeroncologytogether.com/patient](http://www.pfizeroncologytogether.com/patient), 877-744-5675
- ▶ **Sanofi CareASSIST** [www.sanoficareassist.com](http://www.sanoficareassist.com), 833-930-2273
- ▶ **Sanofi Patient Connection** [www.sanofipatientconnection.com](http://www.sanofipatientconnection.com), 888-847-4877

## Clinical Trials Resources

- ▶ **ClinicalTrials.gov** [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- ▶ **National Cancer Institute** [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials), 800-422-6237
- ▶ **NCI Contact Center (cancer information service)** 800-422-6237
- ▶ **ZERO Prostate Cancer** [zerocancer.org/clinical-trials](http://zerocancer.org/clinical-trials)



# Be prepared for side effects

**M**any people are concerned about the side effects caused by cancer treatment. Prostate cancer treatment can be accompanied by physical, emotional and sexual side effects. It is important to remember that you will not have to manage them on your own; you will be supported by your multidisciplinary team.

Before treatment begins, talk with your medical team about possible side effects and what to do if they occur. It is important to remember to communicate honestly about how you feel, both physically and emotionally, with your health care team.

Severe side effects can occur with treatment. Ask your doctor whether you are at risk, how to identify the symptoms and when to seek emergency care. Report symptoms to your health care team immediately if they occur.

Following are some of the most common physical side effects of prostate cancer and its treatment. See Table 1 for others, and ask your doctor about any side effects that you should be aware of.

## URINARY INCONTINENCE

Prostate cancer treatments, such as surgery and radiation therapy, may cause incontinence, which is the inability to control urine flow. It can range from mild to severe.

- **Stress incontinence** happens when the muscle that squeezes the urethra to keep urine in the bladder is weak or damaged, or the nerves that help the muscle work have been damaged. As a result, urine may leak out when you cough, laugh, sneeze, lift heavy objects or exercise. You typically sleep through the night without having to get up to go to the bathroom but have urine leak out when you stand up in the morning.
- **Overflow incontinence** occurs when the bladder does not empty well and the amount of urine made is more than the bladder can hold. Usually caused by a blockage or narrowing caused by scar tissue, overflow incontinence may happen when the bladder muscle cannot squeeze well enough to release all of the urine. Urine may leak throughout the day.
- **Urge incontinence** symptoms are similar to those with an overactive bladder. The bladder muscle, irritated by the radiation, contracts too often, sometimes powerfully

enough to force urine out with little warning. Even a small amount of urine in the bladder can trigger a strong need to urinate, necessitating frequent bathroom trips.

- **Continuous incontinence** occurs when you have no control over the bladder and urine leaks out constantly.

Depending on the cause and whether incontinence is short term or long term, there

are ways that may help manage it. The goal is to continue with your daily life with little disruption. Talk with your health care team so they can work closely with you to determine the best strategies to manage it, which may include the following:

- **Pelvic floor exercises**, commonly known as Kegels (pronounced KEE-gulz), may help reduce leakage from stress incontinence (see *About Kegel Exercises*, page 11).
- **Medications** that will tighten or relax your muscles may be prescribed. They may be most helpful for urge incontinence.
- **Surgery** may help correct long-term incontinence. A surgeon may implant a sling to hold up the bladder or place an artificial urinary sphincter, a device that

▲ TABLE 1

## COMMON PHYSICAL SIDE EFFECTS OF PROSTATE CANCER TREATMENT

*Contact your health care team if you experience any side effects. Some can only be detected by lab work or imaging tests, so it is important to keep follow-up appointments.*

Side Effect*	Description
Anemia	Abnormally low red blood cell count
Bleeding	Blood in the urine or stool
Bone problems	Weak, less dense or thin bones at higher risk for fracture
Bowel incontinence	Stool leakage caused by the inability to control bowel movements
Burning sensation	Stinging during urination caused by some forms of treatment
Chemo brain (cognitive dysfunction)	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or less frequent bowel movements compared to your usual bowel habits
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Dyspnea	Shortness of breath, with or without cough
Erectile dysfunction	Inability to achieve or maintain an erection
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
Infertility	Inability to father a child
Lymphedema	Fluid buildup from lymph node removal that causes swelling
Nausea and vomiting	Upset stomach that may be prevented by anti-nausea medications
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Neutropenia	Low white blood cell count that increases the risk of infection
Pain	Abdominal, muscular or bone discomfort
Sexual dysfunction	Erectile dysfunction, reduced desire or feeling less desirable
Skin reactions	Rash, redness and irritation or dry, flaky or peeling skin that may itch
Urinary incontinence	Inability to control the flow of urine from the bladder
Urinary retention	Inability to completely empty the bladder (bladder may feel full even after urinating)

\*Side effects listed alphabetically. Talk to your doctor about what to expect with your treatment plan.

constricts around the urethra to prevent or reduce leakage. If symptoms do not improve, your doctor may implant an artificial muscle controlled by a scrotal pump to squeeze the urethra.

## ERECTILE DYSFUNCTION

A common side effect of prostate cancer treatment, erectile dysfunction (ED), also called impotence, is a concern of many men. ED is the inability to achieve or maintain an erection and can be caused by several factors:

- Damage during treatment to nerves or blood vessels that supply the penis
- Reduced level of testosterone in the blood resulting from hormone therapy

ED can be intensified if erection problems due to age or other reasons were present before treatment, including preoperative erectile status.

Ask your doctor which treatments may potentially cause ED, whether it will be temporary or permanent and how to manage it. Part of that discussion could include determining whether a nerve-sparing surgery would improve the chances of recovering erections.

After surgery, it takes time to fully regain erectile function. With radiation therapy, erections may not be affected immediately but may begin to fail over time. Approximately the same percentage of men have erectile dysfunction four years after either prostatectomy or radiation therapy. In general, younger men (under 60) are more likely to regain full erections after surgery than older men.

## About Kegel Exercises

➡ When the prostate is removed, the sphincter that connects the bladder to the urethra can be damaged, leading to urinary incontinence. Consider talking to your doctor about learning to do Kegel exercises to help strengthen the muscles that can clamp off the urethra. These exercises may not eliminate your bladder incontinence, but with consistent practice, you could see an improvement.

- 1 Find your pelvic floor muscles to squeeze. One way is to stop urinating midstream. The muscles you squeeze to stop are your pelvic floor muscles.
- 2 Squeeze the pelvic floor muscles.
- 3 Try to hold for 3 seconds or longer. Avoid holding your breath.
- 4 Relax the muscles.
- 5 Try to do 10 to 15 repetitions each time you practice.
- 6 Repeat three times a day.

Your doctor may recommend one or more of the following to manage ED:

- Oral medications may help you achieve and maintain an erection. Tell your doctor about other medications you take to avoid negative interactions between them.
- Penile injections are drugs that may be self-injected into the erectile tissues of the penis to increase blood flow.
- Urethral suppositories are inserted into your urethra with a special applicator. The suppository melts and the drug is absorbed into the lining of the urethra.
- A vacuum erection device involves placing a small pump over the penis to increase blood flow and create an erection.
- A penile prosthesis, an implant put into place with a surgical procedure, may help restore firmness when no other treatments work. Several different types of implants are available.
- A penile constriction ring may be used with other options listed above to maintain an erection. It consists of a stretchy band that sits at the base of the penis.

## FATIGUE

The type of cancer-related fatigue patients may experience is due to the disease and its treatment. It is different from the fatigue that healthy individuals may feel. It can last for months or years after completing treatment. Talk with your doctor if fatigue is impacting you.

Your doctor may suggest one or more of the following:

- Exercise, even a short walk, relieves fatigue. Balance your activity with rest. Save your strength for activities that are most important.
- Maintain good nutrition. Eat a well-balanced diet of fruits, vegetables, protein and water to help promote healing and restore your energy.
- Talk with a counselor to reframe thoughts about fatigue, develop coping skills and overcome sleep problems leading to fatigue.
- Try mind-body strategies. Activities like yoga, mindfulness practices, massage, relaxation, music therapy and acupuncture may help reduce fatigue.
- Medications may help you feel more awake. If the fatigue is due to hormone therapy, certain medicines may help replace these hormones.
- Supplements may be an option to consider if your doctor finds your fatigue is related to a nutritional deficiency.

## PERSONAL CARE PRODUCTS

*You may need to manage urine leaks. Talk to your health care team about products such as these that may help:*

- Absorbent, washable underwear
- Adult briefs (reusable or disposable)
- Waterproof underwear
- Pads for beds and chairs
- Skin cleansers and creams
- Urine deodorizing tablets
- External catheter

## EMOTIONAL WELL-BEING

Facing prostate cancer and its treatment can bring up many emotions and impact your mental health. These feelings are normal, and your medical team can help you address them with services known as palliative care. The goal of palliative care is to improve your quality of life; reduce pain; treat symptoms and side effects; and address psychological, social, financial, dietary and spiritual problems caused by the disease or treatment.

Following are emotions you may have and suggestions for ways to feel better.

**Anxiety** is a feeling of having extra worry, the inability to relax and feeling tense. Explore counseling, support groups, meditation, deep breathing and light exercise.

**Depression** is a mental condition marked by ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. Other symptoms include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death or suicide. Consider talking about your feelings with family members, support groups or counselors; try relaxation exercises; use mindfulness and prayer; and ask about medications that may help.

**Distress** is the feeling of emotional, social, spiritual or physical pain or suffering that may cause a person to feel sad, afraid, depressed, anxious or lonely. People in distress may also feel that they are not able to manage or cope with changes caused by normal life activities or by having a disease, such as cancer. Let your team know if you are feeling distressed.

**A lack of desire** for, or interest in, sex may be due to hormone changes. Be honest with your partner. You may explore other ways to be intimate. ■

# Follow-up care and monitoring help forge your path forward

**F**or some men, when prostate cancer treatment ends and follow-up care begins, your health care provider will provide you with a follow-up care plan that includes a summary of your treatment plan along with a schedule of appointments for physical exams and medical tests. These enable your health care provider to check whether the cancer has returned or spread to other parts of the body and to watch for any other health problems that may develop months or years after treatment ends.

This plan may also include referrals for cancer rehabilitation, such as physical therapy, career counseling, pain management, nutritional planning and emotional counseling. It will include information about your risk of a recurrence or a second cancer and recommended cancer screening guidelines.

Follow-up appointments also give you the opportunity to address new symptoms or concerns. Tell your doctor how you feel physically, mentally and emotionally, or sooner if something changes. Some topics you may want to discuss include:

- Hormone-related symptoms
- Unrelieved pain
- Sexual dysfunction
- Anxiety
- Depression

## MAKING HEALTHY LIFESTYLE CHOICES

Whether or not you are still receiving treatment, leading a healthy lifestyle may help you do the following:

- Build back your strength with nutritious foods
- Reduce your risk of heart disease, high blood pressure, excess weight and diabetes
- Lower anxiety
- Increase positive feelings
- Prevent bone loss (osteoporosis)

**Monitor your bone health.** This is espe-

cially important if you have had hormone therapy because the reduction in testosterone may contribute to bone loss and a lower bone density, which may progress to osteoporosis. If osteoporosis develops, your risk of spontaneous fracture or fracture after a fall is increased. Your health care provider may order a bone density scan to establish a baseline for your bone health. This will help monitor your treatment's effect on your bones and indicate whether bone-strengthening drugs may help.

**Ask your doctor about exercise.** Regular exercise after treatment may help you manage anxiety, maintain a healthy weight, boost muscle strength and endurance, increase self-esteem and improve heart health.

## Consult with your doctor or a dietitian.

Good nutrition gives your body essential nutrients to improve your health. This includes vegetables, fruits, whole grains, lean protein and low-fat dairy products.

**Stop tobacco use.** If you use tobacco products, there is overwhelming evidence that it is best that you quit to improve treatment outcomes, have fewer side effects, recover faster, lower your risk of second cancers or serious cardiovascular or lung disease, give you more energy and improve your quality

of life. Ask your health care team about options to help you.

**Avoid or limit alcohol consumption.** Research shows any amount of alcohol can increase your risk for cancer. If you continue to drink alcohol, limit the amount you consume to two drinks or less a day.

## WATCHING FOR LATE AND LONG-TERM EFFECTS

It is possible for side effects to develop months or years after treatment ends, and these are known as late effects. For others, side effects are more long term, beginning during treatment and continuing after it is finished. To help you manage these effects, communication with your health care team is important. Based on your symptoms, your provider may order certain exams, scans or blood tests to find and manage the effects.

Some common late effects of prostate cancer include the following:

- Anemia
- Anxiety
- Bone problems (osteoporosis)
- Bowel problems (such as diarrhea or constipation)
- Depression
- High blood pressure, high cholesterol and high blood sugar levels
- Hot flashes
- Issues with sexual health, intimacy and body image
- Urinary problems

Ask your doctor about side effects to watch for.

## MAINTENANCE THERAPY

Sometimes continuous or maintenance therapy is needed. Maintenance therapy is given to help prevent cancer from returning after it has disappeared following the initial therapy. It may include treatment with drugs, vaccines or antibodies, and it may be given for a long time. It may also be given to delay the growth of advanced cancer after initial treatment.

Maintenance therapy may be given for weeks to years depending on the cancer, the drugs used, how well treatment worked and the number and severity of side effects. ■

## » Prepare for Scanxiety

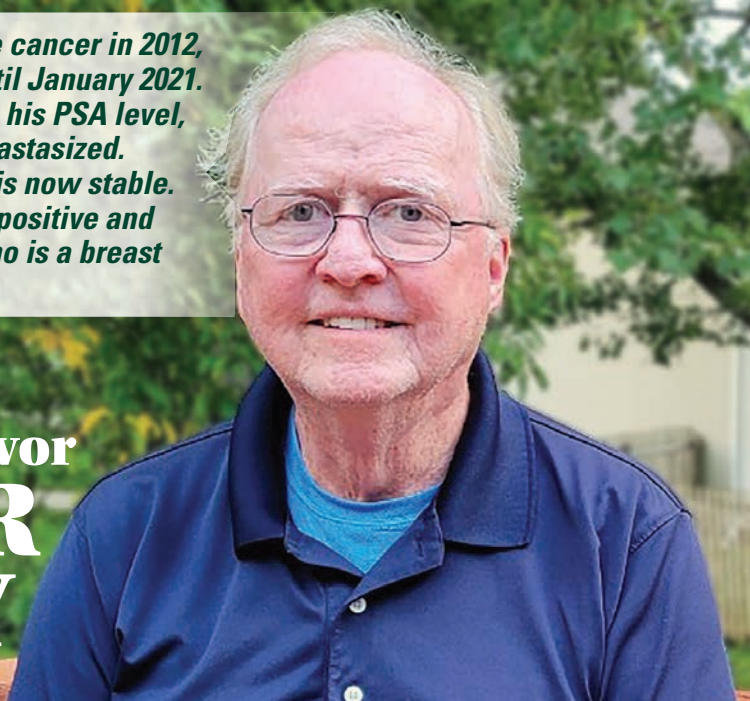
The term "scanxiety" is the feeling of stress or worry you may have before a medical test, during the test and while you wait for results. The tests may be performed for diagnosis, to monitor treatment or to determine whether there is a recurrence. Physical sensations of scanxiety may include trouble eating and sleeping, increased heart rate, irritability, sweaty palms and nausea.

First, remind yourself that it is normal to feel this way. Set expectations with your medical team about when and how you will receive the results so you are not left waiting and wondering. Knowing this information is empowering and can help you manage the uncertainty while you await results.



➔ **First diagnosed with Stage II prostate cancer in 2012, Mike Mulcahy remained in remission until January 2021. Follow-up testing showed an increase in his PSA level, and scans confirmed the cancer had metastasized. After returning to treatment, the disease is now stable. Despite the recurrence, he is optimistic, positive and realistic. He enjoys life with his wife, who is a breast cancer survivor, and his grandchildren.**

## Optimistic metastatic prostate cancer survivor **LIVES FOR EACH DAY**



➔ **After being diagnosed** with aggressive Stage II prostate cancer in 2012 and successfully completing proton radiation and hormone therapy, I had regular follow-up appointments to check my PSA level. For 9 years, my PSA remained at .3 or .4. In January 2021, as I was heading in to get my routine PSA level checked, I chuckled to myself that "I've got this cancer taken care of because it's been too long since I originally had it." I thought I was in the clear. But after the appointment, my doctor called to say my PSA had gone from .3 to 1.7.

The doctor said the lab sometimes makes mistakes, and he wanted me to come back in a week for another PSA test. The second result showed my PSA was now 2.1. It was rising very fast. The doctor ordered a PET and bone scan. They found lesions on my pelvic bone that confirmed I had metastatic prostate cancer.

The first words out of my mouth were, "Oh, crap!" I knew immediately what I was up against. I had mentally prepared for it to return one day, but I wasn't expecting it. I reminded myself that even with metastatic cancer, I would not die tomorrow.

I am being treated at my local Veterans Affairs (VA) hospital because I served in the Marine Corps during the Vietnam War. There are some days you will never forget in life, and one of mine was when I was in Okinawa, Japan, getting ready to be sent to Vietnam. While I was packing my duffel bag, the overhead speakers were broadcasting Neil Armstrong's landing on the moon. I remember thinking, "They put a man on the moon, and down here I'm going to war." It was a surreal moment.

Like most men who served in Vietnam, I was exposed to Agent Orange, which is known for causing up to 12 types of cancer. My VA has extensive experience treating men with prostate cancer, and I feel I'm getting the best care.

To keep the cancer stable and reduce the risk of it spreading, I'm on a hormone therapy regimen. So far, this treatment is working for me. The lesions on my pelvis have shrunk to nothing, my PSA is 0 and I have no symptoms. I will continue getting my PSA level checked and will remain on my treatment for as long as it continues working.

Regarding side effects, I occasionally have hot flashes at night but not during the day.

I call this cancer Sneaky Pete because it can come back when you least expect it. I have the mindset that I'm going to be living with metastatic prostate cancer and will be on disease management medications for the rest of my life. I've accepted it, and I don't worry about it. I have my affairs in order and I'm good to go whenever that is and for whatever reason.

Ironically, having cancer gave me a brighter outlook on life because now I have a better idea of when the end may come. Now when I wake up every day, I think, "What can I do to make my life meaningful?" I've decided to be optimistic and live life to the fullest.

My wife and I enjoy providing childcare for our five grandchildren, and I'm surrounded by my family. This keeps me going. I don't dwell on the rest. ■

### Mike's advice

#### **My advice to other men who have metastatic prostate cancer:**

- ▶ Stay positive. Attitude makes a huge difference.
- ▶ Listen to your doctor.
- ▶ Educate yourself about what to expect.
- ▶ Talk to other men both online and in person. Doctors only have so much time they can spend with you, and they can't tell you everything.
- ▶ If you don't have a relationship with God, get one.
- ▶ Love your family.
- ▶ Get your affairs in order, including having a will, living will and power of attorney. Have the information written down for your children or other loved ones, and tell them where to find the paperwork and documents.
- ▶ Don't be afraid of dying. It is a natural part of life.

# Understanding the role of the caregiver

**H**elping a loved one during a prostate cancer diagnosis and treatment can be a gift. At the same time, it can be very challenging. As a caregiver, you will likely be called on to provide physical, practical and emotional support. As you take on this new role, remember that you don't have to shoulder every responsibility on your own. Use the resources around you to be the most effective caregiver you can be.

You may assist your loved one in a variety of ways:

- Communicating with the health care team
- Managing and giving medications
- Helping track and manage symptoms and side effects
- Coordinating medical appointments
- Driving to and from appointments
- Shopping for and making meals (see *The Role of Nutrition* below)
- Helping with household chores
- Managing insurance and billing issues

These responsibilities could change on a daily basis depending on your loved one's needs. Try to be patient and remain flexible.

Staying organized is also helpful. Create a caregiving plan to help prioritize your responsibilities. Outlining all of the things you currently do, and those you want to do, may make it easier to find opportunities to delegate tasks to others who are looking for ways to show their support. Identify friends or neighbors who are able to do certain tasks that aren't easy for you, such as yardwork or snow shoveling. Don't forget to reach out to your loved one's health care team. They can

offer suggestions for local caregiving companies as well as refer you to local and state organizations. If you are employed, ask your human resources department for information about any services available from your employee assistance program. Also ask about the Family and Medical Leave Act (FMLA).

You can also be a valuable source of support. Whether he is your partner, family member or friend, caring for him will add a new layer to your relationship. Managing prostate cancer is a sensitive topic, and you will have to gauge how your loved one is most comfortable communicating. Sometimes it will be helpful for you to listen; other times, it may be most helpful to simply just be there. Or, your loved one may feel more comfortable talking to a professional, such as a therapist or spiritual advisor, about such

a personal topic. Some organizations also have support groups for caregivers. Talking to other people who are going through the same type of situation can be helpful.

## FOCUS ON YOUR WELL-BEING

One of the most important tasks for caregivers is caring for themselves. That can be challenging because caring for a loved one facing cancer can feel overwhelming, especially if you have other obligations, such as a job, school or caring for children or parents.

Be sure to set aside time for self-care. Managing stress and staying physically and emotionally healthy should be priorities. Remember, it is difficult to take care of someone else if you are struggling.

Try to incorporate these suggestions into your daily life:

- Make and keep your doctor's appointments.
- Follow a nutritious diet.
- Exercise. Even a short walk can boost your mood and help you feel refreshed.
- Maintain a healthy sleep schedule.
- Find a few minutes each day to relax.
- Be hopeful for your loved one and for yourself. ■

## Government Resources

- ▶ **Benefits.gov** [www.benefits.gov](http://www.benefits.gov)
- ▶ **Centers for Medicare & Medicaid Services** [www.cms.gov](http://www.cms.gov)
- ▶ **Hill-Burton Program** [www.hrsa.gov/get-health-care/affordable/hill-burton](http://www.hrsa.gov/get-health-care/affordable/hill-burton), 800-638-0742
- ▶ **Legal Services Corporation** [www.lsc.gov](http://www.lsc.gov), 202-295-1500
- ▶ **Social Security Administration** [www.ssa.gov](http://www.ssa.gov), 800-772-1213
- ▶ **U.S. Department of Veterans Affairs** [www.va.gov/health](http://www.va.gov/health)

## The Role of Nutrition

➔ **Cancer as well as its management** may make it harder for your loved one to get all the nutrients his body needs. Helping him learn and keep good nutrition habits is important. A healthy diet may also contribute to his emotional health.

Involve your loved one in meal planning. Making decisions about the foods he eats may be empowering. Together, with the help of the health care team, you can make a plan that will better position you to address the nutrition-related challenges that accompany a cancer diagnosis.

Ask for a nutrition consultation or referral to a registered dietitian. Encourage your loved one to be honest about any problems he is having with eating or with certain foods. The health care team is experienced in working with people who have cancer and may offer helpful solutions.

In general, a well-balanced diet in terms of cancer includes eating and drinking enough of the foods and liquids that have important nutrients (vitamins, minerals, protein, carbohydrates, fat and water) the body needs.

**Talk to the health care team about these suggestions:**

- ▶ **Drink enough fluids to function and to prevent dehydration.**
- ▶ **Eat a variety of fruits and vegetables.**
- ▶ **Microwave or steam vegetables when cooking to preserve the most nutrients.**
- ▶ **Wash fruits and vegetables well.**
- ▶ **Limit intake of red meat and processed meat.**
- ▶ **Avoid saturated fats.**
- ▶ **Limit alcohol.**
- ▶ **Attempt to maintain a healthy weight.**



# From those who know...

➔ *Learning how other caregivers approached their journeys may be both comforting and helpful*



**“** *The first step was to follow Mike's lead as he began re-searching prostate cancer to choose a method of treatment. Mike's tenacity in gathering information really amazed me. He talked to other men who had faced the same diagnosis, comparing notes on both treatment options and ways to cope. One conversation would lead to another as strangers became supporters, providing both information and encouragement. I was learning along the way, too, but Mike really worked hard to educate himself.*

*If you're helping a husband with prostate cancer, realize that you can talk to him about his cancer over dinner, during a drive to the mall, while you're folding laundry — really any time. Life goes on, and the needs of daily life are still there. But you should also understand that this is an extraordinary time in your lives. Listen carefully to your husband, and graciously accept the help and comfort that others offer to you.”*

~ *Carol, wife of and caregiver for Mike*  
(read Mike's story on page 13)



**“** *Doug and I attend an extremely helpful local support group twice a month. I checked them out and told Doug to come with me when he was ready. They have a meeting that focuses on educating survivors and their family members or caregivers. Another puts prostate cancer survivors and caregivers, which mostly means wives, in separate rooms. We listen to doctors and speakers and then talk about everything — new medicines, tests and ways to manage side effects, exercises, diet and more. We're always sharing and learning from each other.”*

~ *Roxana, wife of and caregiver for Doug, prostate cancer survivor*



**“** *As a caregiver, I learned that I had to try and take care of myself, too. You can't do it 24/7 or you won't be a good caregiver. I knew I just needed to have a positive attitude and to have patience, patience, patience. When you're as close as we are, you realize that you may have been taking things for granted. When cancer hits you, it makes you think a little more and you both toughen up and get through it. The challenge has made us even closer, and I think that as you go through something like this together with each other and your family, it can really make your marriage even stronger.”*

~ *Leila, wife of and caregiver for Jim, prostate cancer survivor*



**“** *Prostate cancer is not just a man's disease; it's a couple's disease, and we had too many questions and not enough answers after Ray's diagnosis. I knew immediately I was going to need to get support if I was going to be of any help to him. We looked for co-ed support groups but didn't have much luck until we finally found a group that welcomed us both and sympathized with what Ray and I were going through.*

*As a caregiver, I had to keep reminding myself that this was his cancer and all I could do was just be there for him, not tell him what to do. So, I went with him to his appointments and organized all of his medical paperwork in a notebook that we took with us to his appointments. I basically just did whatever I could to make life easier on Ray.”*

~ *Linda, wife of and caregiver for Ray, prostate cancer survivor*





# YOUR PERSONAL LABORATORY TEST TRACKER

▲ Keeping track of your laboratory test results, such as those included below, may help you play an active role in treating your prostate cancer.\* Take this worksheet to your appointments to record your results and review them with your

health care team. Ask your doctor about key tests to include and the reference ranges appropriate for you. These ranges may vary among laboratories, and your laboratory should provide additional reference ranges with your test results.

\*Not a complete list. Ask your doctor for your applicable tests and reference ranges.

*Write down your lab results below each test date.*

Tests	Reference Ranges	Date of Laboratory Testing			
<b>PSA and Testosterone</b>					
PSA level					
PSA density					
PSA velocity					
PSA doubling time					
% Free PSA					
Testosterone					
<b>Pathology Report</b>					
Tumor type					
Tumor size					
Gleason score (ex., 3+4)					
Grade group (1-5)					
Surgical margins					
Extraprostatic extension					
Lymph node status					
<b>Biopsy Reports</b>					
Histology (if no cancer, list as "negative")					
Number of cores taken					
Number of cores with cancer					
Gleason score of core with highest score (e.g., 3+3=6)					
Grade group (1-5)					
<b>General Health</b>					
Weight					
Blood pressure (mm Hg)					
Hemoglobin A1C					
Total cholesterol (mg/dL)					
LDL (bad cholesterol) (mg/dL)					
HDL (good cholesterol) (mg/dL)					
Triglycerides (mg/dL)					



# THIS IS **LIVING WITH CANCER**™

**This Is Living With Cancer™** is a program for people living with cancer and those who love them. We provide support and resources for all, regardless of age, income, race, location, tumor type, stage of disease or whether you're on a Pfizer treatment.



## **Cancer screenings and follow-ups can't wait**

Cancer doesn't take breaks. Download tools and resources to help guide conversations with your doctor.



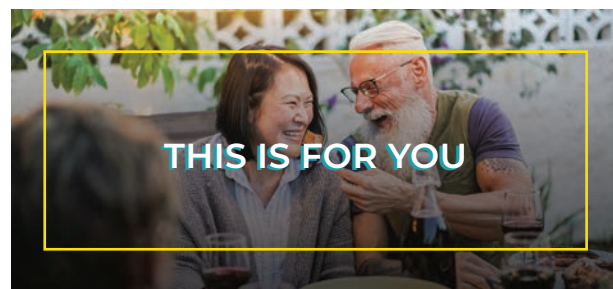
## **Nutrition, exercise and wellness tips**

Get tips from oncology dietitians and fitness experts, and find resources to help you manage your mental health.



## **Resources for adults 65+ and their loved ones**

Find encouragement, education and tools to help you become your best advocate.



## **Support designed with you in mind**

Sharpen your goal planning, stress management and communication skills.

Find tools to help live life beyond your diagnosis at

[ThisIsLivingWithCancer.com](https://www.thisislivingwithcancer.com)



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