

UROLOGYHEALTH extra

NAVIGATING PROSTATE CANCER

ALSO:

Insights on Men's
Health Checklists

Caregiver Story

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A PUBLICATION OF THE UROLOGY CARE FOUNDATION



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Knowledge is power. You do not have to navigate your prostate cancer journey alone. The information in this guide can help you learn more, talk with your family, friends and doctors and make informed decisions. Each person's journey is unique and together we can find a way.

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Look for this icon to learn more as you navigate! You can scan QR codes with your phone camera to learn more from the Urology Care Foundation, powered by trusted experts of the American Urological Association.

How to Navigate PROSTATE CANCER

Prostate Cancer is the second most common cancer in men in the United States. About one in nine men will be diagnosed with prostate cancer during their lifetime. Prostate cancer is more likely to develop in older men and in African American men. Learning you have advanced prostate cancer may be unsettling. You may have a lot to think about, including treatment choices and your future.



“It can be scary to be diagnosed with any type of cancer, including prostate cancer, but it’s important to know you’re not alone. Gathering information about prostate cancer may help you during your prostate cancer journey,” said Daniel W. Lin, MD, a urologist at the University of Washington and Fred Hutchinson Cancer Research Center in Seattle, Washington.

You are not alone during your prostate cancer journey. Your journey may include a team with a primary care physician, oncologist, urologist, pharmacist, social worker and other health care providers, as well as your family and friends.

Men may work with nurse navigators. These health care professionals help a person with cancer “navigate” the hospital and human services that come along with a cancer diagnosis. This may include assisting with decision-making, coordinating services and advocating for the patient with other members of the health care team. Navigators strive to identify barriers to care and eliminate or reduce them to help the patient avoid delays in treatment.

Learning about your prostate, prostate cancer, tests, treatments and side effects may help you during this journey. Your treatment choices should be based on your personal health and age and should be fully discussed with your health care team.

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What is Prostate Cancer?

Cancer is the result of abnormal cell growth that takes over the body’s normal cell function, making it harder for the body to work the way it should. Prostate cancer develops when abnormal cells form and grow in the prostate gland. When prostate cancer spreads beyond the prostate or returns after treatment, it is often called advanced prostate cancer. Prostate cancer is often grouped into four stages, with stages III and IV being more advanced prostate cancer.

Stages of Prostate Cancer

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

Signs of Prostate Cancer

Men with prostate cancer usually do not have any symptoms, but in more advanced stages may have some signs of sickness. Symptoms depend on the size of the growth and where the cancer has spread in the body. In more advanced stages, you may have problems passing urine or see blood in your urine and some men may feel tired, weak or lose weight. When prostate cancer spreads to bones, you may have bone pain. Tell your doctor and nurse about any pain or other symptoms you feel. There are treatments that they can discuss with you.

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

PSA blood test measures a protein in your blood called the prostate-specific antigen (PSA). Only the prostate and prostate cancers make PSA. A rapid rise in PSA may be a sign something is wrong.

Digital rectal exam is a physical exam used to help your doctor feel for changes in your prostate. This test is also used to screen for cancer, stage cancer and track how well treatment is going.

Imaging and scans help doctors learn more about your cancer. Some types are:

- **Magnetic resonance imaging (MRI)** can give a very clear picture of the prostate and show if the cancer has spread into the seminal vesicles or nearby tissues.
- **Computed tomography (CT)** scan is used to see cross-sectional views of tissue and organs.
- **Positron emission tomography (PET)** scan may help your doctor better see where and how much the cancer is growing.
- **Bone scan** can help show if cancer has reached the bones. If prostate cancer spreads to distant sites, it often goes to the bones first.

Biopsy is a tissue sample taken from your prostate or other organs to look for cancer cells. Men may start with a prostate biopsy.

Grading: If a biopsy results in cancer, the pathologist gives it a grade. The most common grading system is called the Gleason grading system. The Gleason score is a measure of how quickly the cancer cells can grow and affect other tissue. The Gleason score will help your doctor understand if the cancer is a low-, intermediate- or high-risk disease.

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

Treatment Options

Early-stage Prostate Cancer

Early-stage prostate cancer is a cancer that has grown in the prostate, but not grown beyond the prostate capsule to other parts of the body, like lymph nodes or bones. Men with early-stage prostate cancer have a very good chance of survival. Here are some types of treatments that you and your doctor may discuss if you’re diagnosed with early-stage, localized prostate cancer.

- Active Surveillance
- Surgery (Radical Prostatectomy)
- Radiation Therapy

Advanced Prostate Cancer

When prostate cancer spreads beyond the prostate or returns after treatment, it is often called advanced prostate cancer. Advanced prostate cancer is not “curable,” but there are many ways to treat it. Treatment can help slow advanced prostate cancer progression.

There are many treatment choices for advanced prostate cancer. Which treatment to use, and when, will depend on discussions with your doctor. Here are the treatments you may want to discuss with your doctor if you are diagnosed with advanced prostate cancer.

- Hormone Therapy
- Chemotherapy
- Immunotherapy
- Combination Therapy
- Bone-Targeted Therapy
- Radiation Therapy
- Active Surveillance
- Targeted Therapy

Talk to your doctor to see if a clinical trial might be right for you.

Your Care Team Should Know What Matters to You

The prostate cancer journey is unique to each person and their family. It is of great importance to learn as much as you can and find the right tools and to let your care team know what is important to you. Talking with your doctor and health care team is a great place to start. Here are some questions you may want to think about asking your doctor as you navigate along the way:

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

“It can be scary to be diagnosed with any type of cancer, including prostate cancer, but it’s important to know you’re not alone. Gathering information about prostate cancer may help you during your prostate cancer journey”

- Daniel W. Lin, MD

The prostate cancer journey can be different for each person and their family. Talking with your doctor and health care team is a great place to start.

Did You Know?

PROSTATE CANCER RISK FACTORS

There are many risk factors for getting prostate cancer. Some you can change, while others you can't.

Your risks for prostate cancer rise if you are age 65 or older, have a family history of prostate cancer, are African American or have inherited mutations of the BRCA1 or BRCA2 genes. Risk factors you can't change include age, race and ethnicity, gender and family history of cancer.

Age: For all men, prostate cancer risk goes up with age. About 6 in 10 cases of prostate cancer are found in men older than 65. Prostate cancer is rare in men under the age of 40.

Race/ethnicity: African American men and Caribbean men of African ancestry face a higher risk for being diagnosed with prostate cancer. They are also more likely to be diagnosed with prostate cancer at younger ages. It is not clear why prostate cancer affects African American men more than other racial/ethnic groups.

Genetic Factors: The risk of prostate cancer more than doubles in men with a family history of prostate cancer in their grandfathers, fathers or brothers. Having family members with breast and ovarian cancer also raises a man's risk for prostate cancer. That is because breast, ovarian and prostate cancers share some of the same genes, including BRCA1 and BRCA2. If a person has any of these mutations, they should be screened earlier or more often for prostate cancer.

Being exposed to harmful chemicals may put you at risk for prostate cancer. Some special groups may be at higher risk to include those who work in farming, factories, fire and rescue, research labs as well as those who are veterans or in active duty with the military.



Expand Your Journey

Scan this QR code with your phone camera to learn more.



TIPS FOR MEN TO CREATE A HEALTH CHECKLIST

NUMBERS TO KNOW

WHAT DO MEN NEED TO KNOW TO STAY HEALTHY?

Many men may have been taught how to fix a flat tire, a leaky faucet or even how to patch a hole in the wall, but do you know what you can do to stay healthy? Routine checkups can spot a number of conditions that can impact a man’s health, including prostate cancer. Many screenings and checkups can be planned, so it is good to know why you need them and how often to have them. Talk to your doctor about your overall health, screenings and tips for healthy living.

Learning about cancer may help you keep your health in check. The top three cancers for men are prostate, lung and colorectal – this excludes skin cancer.



PROSTATE



LUNG



COLORECTAL

WHAT SHOULD MEN KEEP ON THEIR HEALTH CHECKLIST?

For men, urology includes the urinary tract and the male reproductive organs, or, you could think of them as the systems below the belt. Below are some other healthy living tips to keep in mind for your health checklist:

- 120/80 MM Hg is normal blood pressure range
- Normal BMI for men is 18.5-24.9
- Preferred cholesterol range is less than 200 mg/dL
- 7 to 9 is the recommended hours of sleep for adults

These are general recommendations. Talk to your doctor about what is right for you.



120/80 MM Hg is normal blood pressure range



Normal BMI for men is 18.5-24.9



Preferred cholesterol range is less than 200 mg/dL



7 to 9 is the recommended hours of sleep for adults



Expand Your Journey

Scan this QR code with your phone camera to learn more about Latino Men’s Health Checklists.



Garlic Parmesan Flounder with Asparagus

🕒 Total: 25 m 🍴 Prep: 10 m 👤 Serves: 4

302 calories, 19 g fat, 858 mg sodium, 8 g carbohydrates, 3 g fiber, 27 g protein, 180 mg calcium, 3 mg iron, 543 mg potassium, 10 mg vitamin C

This one-pan meal combines flounder, asparagus, garlic and a Parmesan topping for a meal that looks as good as it tastes! If you want to add more fish into your food plan, try this simple dish. Always consult your doctor before making any dietary changes.

Ingredients

4 flounder fillets (about 6 ounces each)	¼ teaspoon black pepper, cracked
1 pound asparagus	6 cloves garlic, minced
3 tablespoons olive oil	½ cup Parmesan cheese, shredded
¼ teaspoon salt	2 tablespoons fresh parsley, chopped

Preheat the oven to 400°F.

1. Line a baking sheet with parchment paper.
2. Place flounder fillets in the middle of the baking sheet and asparagus around it.
3. Brush fish and asparagus with olive oil. Sprinkle with salt and cracked black pepper.
4. Spread minced garlic on top and top with shredded Parmesan cheese.
5. Bake for about 15 minutes or until flounder is cooked through and flaky.
6. Sprinkle with freshly chopped parsley and serve.



Expand Your Journey... through Food!

Scan this QR code with your phone camera to get more healthy recipes.



ASK THE EXPERTS

Q&A



Dr. Kristen Scarpato, a urologist at Vanderbilt University Medical Center, focuses on bladder cancer, genitourinary cancer, prostate cancer, prostatectomy and ultrasound fusion biopsy/artemis.

HOW CAN GENETIC TESTING HELP TREATMENT?

DR. KRISTEN SCARPATO

As a health care tool, genetic test results may help determine if a certain treatment would be helpful. Your doctor may suggest genetic testing because of family history or because you have an aggressive prostate cancer. Genetic testing looks for certain inherited changes (mutations) in a person's genes and can help determine if a cancer is hereditary. To find out if you have a genetic mutation linked to prostate cancer, your doctor may suggest a simple blood or saliva test.

Talking to your doctor may help to find the best testing and treatment options for you.



Dr. Kyle A. Richards, a urologic oncologist at University of Wisconsin School of Medicine and Public Health and Chief of Urology at William S. Middleton Memorial VA Hospital, focuses on prostate cancer, bladder cancer and continent urinary diversions.

WILL PROSTATE CANCER CAUSE URINE LEAKAGE?

DR. KYLE A. RICHARDS

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

- Stress Urinary Incontinence (SUI), when urine leaks with coughing, laughing, sneezing or exercising or with any additional pressure on the pelvic floor muscles. This is the most common type.
- Urge Incontinence, or the sudden urge to pass urine, even when the bladder is not full, because the bladder is overly sensitive. This might be called overactive bladder (OAB).
- Mixed Incontinence, a combination of stress and urge incontinence with symptoms from both types.

Because incontinence may affect your physical and emotional recovery, it is important to understand how to manage this problem. There are treatment choices that may help incontinence. Talk with your doctor before trying any of these options.

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



Dr. Akanksha Mehta, a urologist at Emory University School of Medicine, focuses on male reproductive and sexual medicine.

HOW DOES SEXUAL HEALTH CHANGE WITH PROSTATE CANCER?

DR. AKANKSHA MEHTA

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

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

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

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

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

CAREGIVER STORY: LILLIE SHOCKNEY

Shared Decision-Making, Patient-Centered Care and Coping through the Eyes of a Nurse Navigator

To put it mildly, Lillie Shockney's credentials are impressive. She is a University Distinguished Service Professor of Breast Cancer and full professor within the Department of Surgery at the Johns Hopkins University School of Medicine. She is also the co-developer of a program called Work Stride - Managing Cancer at Work, with Johns Hopkins Healthcare Solutions. She worked as the administrative director of the breast center at Johns Hopkins for over 20 years as well as the director of their cancer survivorship programs for 7 years. Her total time working at Johns Hopkins exceeds 40 years. She founded the Academy of Oncology Nurse and Patient Navigators 11 years ago. In simple terms, she works as an oncology nurse navigator and patient advocate.

Aside from her wide career accomplishments, Lillie knows what it is like to get news from a doctor that each patient fears. She is a two-time breast cancer survivor and was part of a diverse caregiving team for her dad during his battle with prostate



cancer, which spread to other parts of his body. She knows what it is like to be both a cancer patient and a cancer patient caregiver.

In her role as an oncology nurse navigator, she helps people with cancer navigate the hospital and human aid needs that come along with having cancer. She helps with decision making, so that it is a shared decision-making process, helping to plan care and advocating for the patient with the other members of the care team. Through her work,

she has seen many patients with barriers to their care that may include health insurance, cultural and learning challenges or fears that may cause a patient to decline recommended care. Nurse navigators strive to find all the barriers to care and get rid of them quickly so the patient has no delays in care.

In her work and through her caregiving role, Lillie focuses on patient-centered care. Lillie says,

The patient is more than their diagnosis. They had a life, and we want them to still have a life while being treated for this disease. Do they have a family? What is important to them? What are they most worried about? What brings them joy?

All those things need to be factored into the health care planning, but most importantly, those goals of care need to be understood. I feel as if it is of great value to sit down with the family to highlight what the patient desires, and that the patient should make choices together with the health care team. It should not be driven by adult children saying, "Dad, I want you to do this for me." Because that really is not fair. It is of great value to allow your loved one to take the lead.

Lillie is always thinking of new ways to care for patients and their loved ones with advanced disease.

She has carried out many retreats for breast cancer patients and their family caregivers over the years. She conducted a retreat for patients and their spouses dealing with prostate cancer too. Feeling out of control can be normal when faced with cancer. Through Lillie's work, she hopes to give cancer patients and their loved ones the tools and support they need to maintain a good quality of life.

"The patient is more than their diagnosis. They had a life, and we want them to still have a life while being treated for this disease. Do they have a family? What is important to them? What are they most worried about? What brings them joy?"



Expand Your Journey

Scan QR code with phone camera to listen to Lillie's story and other caregivers who are part of the prostate cancer journey.



UROLOGY MYTHBUSTERS



FACT OR FICTION:

Clinical Trials are Never an Option for Patients

Myth. Clinical trials are research studies that test new treatments or learn how to use existing treatments better. Clinical studies aim to find the treatment strategies that work best for certain illnesses or groups of people. For some patients, taking part in a clinical trial may be an option. Clinical trials follow strict scientific standards. These standards help protect patients and help produce reliable study results. All of the approved treatments used to treat or cure cancer began in a clinical trial. Talk to your doctor to see if a clinical trial is an option for you.

FICTION



FACT OR FICTION:

Appropriate Exercise May Help

Truth. Exercise may improve your physical and emotional health. It may also help you manage your weight, maintain muscle and bone strength. Always talk with your doctor before starting or changing your exercise routine. If approved by your doctor, men may want to strive to exercise about one to three hours per week. Cardiovascular exercise and strength/resistance training may be good choices. Physical exercise may help you to reduce anxiety, improve energy, improve self-esteem, feel more hopeful, improve heart health, reach a healthy weight, boost muscle strength and maintain bone health.

FACT



FACT OR FICTION:

Managing Prostate Cancer is a Team Effort

Truth. Cancer care consists of a team of doctors and health professionals from many areas who work to create a treatment plan that is right for you. These “team leaders” who help treat prostate cancer include a urologist, radiation oncologist and an oncologist. A cancer care team can include other specialists like nurse practitioners, nurses, nutritionists, social workers and rehabilitation specialists. Each team member plays a role in your cancer care journey.

FACT

Stressed about money, romance, urine leaks, palliative care or how to navigate? Try talking about it.

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

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

Prostate Cancer Caregiver Podcast Series



**Daniela A. Wittmann,
PhD, LMSW**

Social worker discusses the important issue of sexual health of men living with prostate cancer, including information for their partners.



Brian Keith McNeil, MD, FACS

A doctor provides his perspective on treating prostate cancer patients and taking care of his father who passed away from the disease.



**Anne E. Calvaresi, DNP,
CRNP, RNFA**

An advanced practice provider shares her experience concentrating on her career in prostate cancer.



Silvia Cooper

A multi-generational caregiver provides the perspective of an advocate.



**Lillie D. Shockney, RN, BS,
MAS, HON-ONN_CG**

A daughter who cared for her father with prostate cancer talks about the role of a nurse navigator and shared decision-making.



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