Voices of Prostate Cancer

ALSO:
Prostate Cancer Diagnosis
Latest Recommendations for Prostate Cancer
Innovations in Prostate Cancer

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The Importance of Having a Second Set of Ears

Prostate cancer was the last thing on my mind when I took part in a Pro Football Hall of Fame health and screening event nearly 10 years ago. So when my urologist called and asked my wife and I to come into his office to discuss my test results, and then told me I had prostate cancer, I really didn’t hear much of anything else. Fortunately, my wife was prepared, and asked a lot of questions. She also took many notes including details about my PSA and Gleason scores, as well as information about my treatment options. I was fortunate that my urologist recognized the importance of including my wife in the discussion. From that point forward, my wife was with me at every visit and we had paper and pencil in hand for every discussion. Encourage your patients to bring someone with them to every visit. Sometimes we only hear what we want to hear, but our second set of ears, hears everything else.

— JANET M. JONES; AUTHOR AND WIFE OF METASTATIC PROSTATE CANCER PATIENT, EUVON JONES
Be Willing to Communicate Outside the Exam Room

When you are metastatic like me, headaches, bone pain, swelling in the legs and hot flashes are side effects that can often occur from treatment and progression. Sometimes I’m not sure if these side effects are normal or are considered a medical situation that I should been seen for. Because of this, I or my wife may call the office to speak with someone on my care team. I recognize everyone is busy, which is why when someone responds to my inquiry or question that same day, it is so very much appreciated. Many men like me would prefer to stay in contact, so don’t be afraid to interact with us through mail, phone or text.

How Long Will These Side Effects Last?

All prostate cancer treatments can cause side effects. That’s why knowing more about the side effects that come along with a specific treatment option is crucial. Discussing all applicable treatment options, including their goals and side effects, is key to helping make a decision that best fits an individual’s needs. Telling me to expect a certain side effect is one thing, but educating me prior to treatment about ways to possibly mitigate their full impact is completely different, and helpful. While I recognize every man is different, knowing how long they are likely to persist and how they may impact my day-to-day routine, and quality of life, is also very helpful in shaping my recovery expectations.
PROSTATE CANCER DIAGNOSIS
WEIGHING THE RISKS AND BENEFITS OF NEW TESTS AND RECOMMENDATIONS
In recent years, there has been controversy surrounding prostate-specific antigen (PSA)-based screening. Some experts recommend against routine PSA screenings for prostate cancer as they believe the ratio of potential benefit to harm is so small. The U.S. Preventive Services Task Force (USPSTF), for example, recommends against PSA screening altogether because they feel it can lead to unnecessary biopsies and overtreatment for men with prostate cancer that could otherwise be left alone. However, many experts on the matter, including the American Urological Association, believe early detection is key and the appropriateness of PSA screening should be based on a decision made between the patient and his physician after discussing the man’s medical history, risk level for the disease and benefits/risks of the test.

“When the PSA test first came out, it was widely adopted and expectations for the test were not balanced with the potential harms,” says H. Ballentine Carter, MD, professor of urology and oncology at Johns Hopkins University School of Medicine. “We now have better strategies to reduce harm and other tests to help determine the best plan of action for dealing with prostate cancer— if action is needed at all.”

Emerging Biomarker Tests

Urology researchers are exploring newer tests beyond the standard PSA test to better identify clinically-significant prostate cancer. These tests can help doctors and patients jointly decide whether to monitor PSA levels or pursue a biopsy. An example is the 4Kscore. This blood-based test combines four existing test measures: Total PSA (tPSA), free PSA (fPSA), intact PSA, and human kallikrein 2 (hK2). The 4Kscore also considers prior biopsy status, age, and DRE results before calculating the likelihood that a biopsy would find an aggressive prostate cancer (Gleason ≥7).

Another blood-based test that helps to calculate the likelihood that a biopsy will find cancer is the Prostate Health Index (phi). Phi combines existing tests including the total PSA, free PSA and proPSA, and has greater specificity (80–95%) for distinguishing between high grade and low grade prostate cancers, compared with the PSA or percentage free PSA. In 2012, phi was approved by the FDA for use in men with serum PSA values between 4 and 10ng/ml.

In addition, urine-based tests, like the Michigan Prostate Score (MiPS), use genetic information to estimate a man’s risk of aggressive prostate cancer. MiPS combines the amount of serum PSA with the amounts of two genes, T2:ERG and PCA3, in the urine to predict a man’s risk for developing aggressive prostate cancer. Another urine-based test, called SelectMDx, looks for gene fragments to determine if a man’s prostate cancer is likely to be aggressive. The test measures mRNA levels of the DLX1 and HOXC6, while using KLK3 expression as the internal reference.

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Better Biopsies

With the standard 12-core prostate biopsy (6 cores from each side of the prostate), up to 25 percent of prostate cancer cases are missed due to the way the tissues are sampled. To help reduce missed cases, a test called ConfirmMDx scans biopsied tissue to determine if additional biopsies are needed. A 2013 study published in The Journal of Urology® showed that ConfirmMDx was able to pick up two-thirds of the prostate cancers that were missed on the first biopsy. Approximately 90 percent of men had no cancer on repeat biopsy when the test was negative.

Another way to avoid missing an important cancer is to use MRI to help target the biopsy. Transrectal ultrasound (TRUS) is still the recommended method for initial biopsies. Targeted biopsy techniques include the TRUS-MRI fusion, which merges a stored MRI image with an ultrasound image taken in real-time. Other targeted biopsy techniques include visual or cognitive targeting in which guiding with ultrasound is based on an MRI image. Saturation biopsy techniques (≥20 cores) may provide some benefit over the standard 12-core biopsy; however, these techniques should be used in men at very high risk and with a history of negative biopsies.

Gil Seibel recognizes the value these tests can have in detecting prostate cancer. In 1999, a prostate biopsy missed his prostate cancer. It wasn’t until he underwent another biopsy in 2005 that he learned he had stage 4 prostate cancer. “My initial prostate biopsy was negative so I thought I was in the clear,” says Seibel. “Things would be different for me today if these new tests were available then.”

Today, Gil is a leader of several support groups for men living with the disease, as well as, an advocate for the early detection of prostate cancer. His aim is to prevent other men from experiencing what he’s had to go through over the past 11 years. “Relative to early detection, we have somewhat of an uphill climb because of the USPSTF recommendations against PSA screening,” says Seibel. “But the solution isn’t to stop screening, it’s to educate men and physicians about the importance of early detection and shared decision making and how, through more precise testing, there’s less of a chance a man will be told he has metastatic prostate cancer.”
Working Together with Patients

When Philip Shulka was diagnosed with prostate cancer 15 years ago, there weren’t a lot of resources for men dealing with prostate cancer. After getting a PSA test and biopsy, Mr. Shulka opted for prostate surgery and experienced many of the complications that may come with it like urine leakage and erectile dysfunction. Today, he is a recovery coach with Chesapeake Urology’s patient navigation program in Maryland. He encourages men to be involved in their care, to ask questions and to be their own health advocate. “I don’t give medical advice, but I’m glad to share strategies for dealing with the disease,” says Shulka.

Stacy Loeb, MD, assistant professor of urology and population health at New York University reminds us that there is no perfect test. And, just because a test is new, doesn’t mean that it’s appropriate or useful for everyone. “I offer a baseline PSA test for my patients. From there, we can work together to decide on the next steps,” says Loeb. She notes that the PSA test itself is a blood test, which is not harmful. “It’s the decisions that follow the test that need to be weighed carefully to reduce harm and unnecessary treatment.”

SOUND BITES

“All the doctors on my team have been very supportive. There are many things you can do, based on your stage of prostate cancer. I’ve been involved in selecting my treatment and I give my doctor credit for providing me not only with the options to maintain my quality of life, but for also walking alongside of me throughout the process.”

– EUVON JONES, DIAGNOSED: 2011

BEYOND INITIAL DIAGNOSIS

Prostate cancer is the second-most commonly diagnosed cancer and accounts for more than one-quarter of newly diagnosed cancer in U.S. men. Since the introduction of the PSA test, an increasing amount of men are diagnosed with the disease at an earlier stage. As a result, many are able to opt for such management strategies as active surveillance, surgery or radiation. Signs of progression are carefully monitored through periodic PSA tests and repeat biopsies.

If PSA levels begin to rise after radiation or surgery, patients with biochemical recurrence are often treated with hormonal therapies. Once on these therapies, continued PSA tests, plus testosterone monitoring is important, as a fraction of these patients may develop castration-resistant prostate cancer (CRPC), with or without metastases. In patients with CRPC, bone scans and other imaging techniques are essential to ruling out the presence of metastases or micrometastases. Assessing the risk of non-metastatic CRPC (nmCRPC) progression is primarily evaluated through PSA kinetics, which is why ongoing surveillance and periodic staging assessments, including bone and CT scans, are essential to identifying those most at risk for progression and those who may benefit from additional treatments. This is especially important given the frequency of asymptomatic metastasis in men thought to have nmCRPC. Clinical trials recruiting patients with nmCRPC have struggled with high levels of inclusion screening failures due to the detection of small metastases not identified during initial assessment.

Both the ENTHUSE and IMAAGEN studies shed further light on this issue. The ENTHUSE study included roughly 2,500 men and found that approximately 45 percent of men had previously undetected metastatic disease; therefore were ineligible for study inclusion. Similarly, the IMAAGEN study had a high percentage of patients who failed study screening - 37 percent of high-risk CRPC patients (PSA ≥10ng/mL or PSADT), had previously undetected metastatic disease.

The Prostate Cancer Radiographic Assessments for Detection of Advanced Recurrence (RADAR) Group recommends that, in nmCRPC, the first imaging scan should occur when the PSA level is ≥ 2 ng/mL. If that scan is negative, repeat imaging should occur when the PSA level is 5 ng/mL and with every subsequent doubling of PSA.
Keeping Current on the Latest Recommendations for Prostate Cancer

There are so many diets and dietary supplements out there for cancer patients. While some have passed the test of time, others have been negated or altered based on recent studies. Keeping up to date on the latest recommendations can help patients fight the disease and feel better.

SOUND BITES

“I’ve had surgery and hormonal treatments – I’ve experienced hot flashes and frequency and degree increase. After my surgery, the problem was incontinence. I have to wear Depends. In addition, I have swelling of the ankles and legs. I have to wear stockings. It’s a major issue in the summer when you want to wear shorts. Those side effect factors were never really discussed – I wish they had been.”

– ROB GORDON, DIAGNOSED: 2015
1. **HEART HEALTHY = PROSTATE HEALTHY**

Whether a man has recently been diagnosed with prostate cancer or is currently undergoing treatment, there is one simple rule that still holds true—a lifestyle that is considered good for the heart is also considered good for the prostate. Lowering or normalizing blood pressure, blood sugar, cholesterol or weight (which are all tied to heart health), exercising (3 hours or more per week) and eating a diet rich in fish, poultry, plant-based proteins, vegetables, fruits and whole grains, boosts prostate health and lowers the risk of developing aggressive prostate cancers. The same holds true for those currently going through prostate cancer treatment. Keeping with a heart-healthy diet and exercise routine ensures that the body is getting the proper nutrients, vitamins and minerals essential to maintaining strong bone health and higher energy levels.

2. **LESS IS MORE!**

In the past, vitamins and dietary supplements have been recommended in the fight against prostate cancer, sometimes at very high dosages. However, recent studies suggest that less is actually more! Individual doses of vitamins and supplements (such as selenium, vitamin E and zinc), which were once thought to have protective effects against prostate cancer, have been shown to actually increase a man’s prostate cancer risk and encourage the growth of prostate cancer when taken in high doses. Therefore, men may be better off taking a multivitamin with less of a dose of each vitamin than taking higher dosages of individual vitamins.

3. **SUPPLEMENTS FOR SPECIFIC SIDE EFFECTS? YES!**

If supplements don’t really treat prostate cancer and some are now even considered harmful, then can they be helpful in some other way with prostate cancer? Interestingly enough, yes! New studies have shown that some supplements can reduce the side effects associated with prostate cancer treatments. One of those supplements is American Ginseng (Panax quinquefolius). In a large clinical trial, prostate, breast and other cancer patients who took up to 2000mg a day of American Ginseng were shown to have lower levels of cancer-related fatigue (CRF) after just eight weeks. Great news!

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**Living Healthy**

Eating a healthy, nutritious diet is extremely important for patients to consider during prostate cancer treatment, as well as for recovery after treatment. Below is a personal recipe from the kitchen of metastatic prostate cancer patient, Euvon Jones and his wife, Janet M. Jones, who developed a diet to maximize Euvon’s overall health, while minimizing the side effects of his hormone therapy. Feel free to share this recipe with your patients:

**THAT FAMOUS CHICKEN SOUP**

**Ingredients**

- 1 or 2 cups of organic chicken breast, cubed
- 4 cups organic chicken stock
- Organic Abba’s oil
- 2 cups water
- 2 cloves garlic, minced
- Celtic salt, pepper, turmeric
- 2 stalks organic celery, cubed
- Organic thyme
- 2 organic carrots, cubed
- Organic cilantro
- 2 organic tomatoes, chopped

**Preparation**

1. Sauté garlic, onion, celery, carrots and chicken in oil on low.
2. Add chicken stock and water. Bring to a boil.
3. Cover and simmer for a few minutes.
4. Add tomatoes and continue to simmer until tomatoes are tender.
5. Season with celtic salt, pepper, turmeric, thyme and cilantro at the end of cooking.
6. Toast a slice of organic whole wheat bread and spread with homemade ghee (optional).

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For additional recipes or to learn more about Euvon and Janet’s prostate cancer journey read: *The Trial of Stage IV Prostate Cancer: A Wife’s Case for Faith, Hope and Help*
Giving the diagnosis of prostate cancer to patients is not something that ever comes easy to us. However, as physicians, we strive to communicate the news by using a balance of informative facts and hopeful treatment options in order to shape the lives of our patients. Adding in some real-life patient experiences may further help to define the treatment option that is right for them.

We usually begin explaining to our patients exactly what the prostate is, where it is located, and what it does: It is a small, walnut-shaped gland found only in males that forms a ring around the urethra. It contains cells that make fluid (semen) to protect and nourish sperm. Then we may move on to explain what prostate cancer is and some of the more positive statistics: It is one of the most common cancers in men in the US, and there are nearly 3 million men living as “survivors” in the US. Perhaps we then feel compelled to share the more serious data: About 180,000 new cases of prostate cancer will be diagnosed this year, and about 27,500 men will die from the disease. Mixing in the value of today’s science and how far we have come in treating prostate cancer makes those grave numbers less scary and gives additional hope. It is at this point that we tend to start drilling down into the specific nature of the patient’s individual case.

A good way to begin is by reviewing the four stages of prostate cancer with him:

**Stage 1:** The tumor in the prostate is so small; it is only visible with a microscope.

**Stage 2:** The tumor has grown bigger inside the prostate, but not to nearby tissues.

**Stage 3:** The cancer has spread outside the prostate, but only to nearby tissues.

**Stage 4:** The cancer has spread outside the prostate to other more distant tissues, most often to the lymph nodes and bones. This stage is known as “metastatic prostate cancer.”

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**SHAPING LIVES: TREATING PROSTATE CANCER**

**SOUND BITES**

“One of the toughest things in dealing with prostate cancer is deciding what treatment to have. That’s why it’s important to know as much as possible about what treatment options are available, what all the side effects of each can be, how long the treatment takes and how long the side effects will last. We fear what we don’t know which is why discussing these topics, and making a decision together, as doctor and patient, is so important.”

– PHIL SCHULKA, DIAGNOSED: 2007
Next, we can assess the patient’s current risk grouping, treatment options and treatment option risks with him. The important thing to remember is to be positive as there are many treatment choices available for very low risk patients to even the most advanced. As we know, although there is no cure for metastatic prostate cancer, there are still many different options to treat it. Remember to explain that no one treatment is right for everyone. The following chart may be a good way for you to review this information with your patient.

Finally, sometimes our patients find comfort in the experiences of other prostate cancer patients and survivors. Reading their stories and learning how they have dealt with their diagnosis and treatment options may help to shape their own choices. Consider sharing this information with your patients as well.

The physician’s role of helping to shape the lives of our prostate cancer patients is an incredible responsibility. Using a combination of facts, treatment options, risks and other patient experiences can make this job easier for ourselves and, ultimately, for our patients.

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<th>Initial Treatment Options</th>
<th>Treatment Benefits</th>
<th>Treatment Risks</th>
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<tbody>
<tr>
<td>VERY LOW RISK</td>
<td>10 to &lt;20 years</td>
<td>Active Surveillance</td>
<td>Avoid side effects of any unnecessary definitive therapy; retain quality of life and normal activities; reduce risk of treating small, indolent cancers; and lower costs</td>
<td>Cancer could grow and spread between tests</td>
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<td></td>
<td>&gt;20 years</td>
<td>Radiation Therapy (RT) or Brachytherapy</td>
<td>Less invasive than surgery to treat early stage prostate cancer</td>
<td>Leaves the prostate in the body; can include a treatment course of up to 9 weeks; surgery is difficult if cancer comes back; side effects may include: blood in urine, bladder or bowel problems and erectile dysfunction</td>
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<td>&gt;20 years</td>
<td>Radical Prostatectomy (RP)</td>
<td>Removes cancer with the prostate</td>
<td>Surgical side effects include: bleeding, erectile dysfunction and loss of bladder control</td>
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<td></td>
<td>&lt;10 years</td>
<td>Observation (“Watchful Waiting”)</td>
<td>Avoid biopsies; avoid side effects from other treatment options; maintain quality of life and normal activities</td>
<td>Cancer could grow and spread</td>
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<td>LOW RISK</td>
<td>&gt;10 years</td>
<td>Active Surveillance</td>
<td>Same as Above</td>
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<td></td>
<td>&lt;10 years</td>
<td>RT or Brachytherapy</td>
<td>Same as Above</td>
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<td>RP</td>
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<td>INTERMEDIATE RISK**</td>
<td>&gt;10 years</td>
<td>RP or RT +/- Androgen Deprivation (ADT) +/- Brachytherapy</td>
<td>Nausea, vomiting, hot flashes, loss of libido, loss of muscle mass and strength, anemia, feeling tired, osteoporosis, swollen/tender breasts, ED and greater risk for diabetes and heart disease (in older men)</td>
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<td>&lt;10 years</td>
<td>RT +/- Androgen Deprivation (ADT) +/- Brachytherapy</td>
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<td>HIGH RISK**</td>
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* Risk grouping and treatment options based on National Comprehensive Cancer Network® Guideline for prostate cancer
** Patients with multiple adverse factors may be shifted into the next highest risk group.
INNOVATIONS IN PROSTATE CANCER

Every day, researchers are discovering new and better ways to prevent, diagnose and treat prostate cancer. Learn more about these innovative discoveries, as well as, the importance of clinical trials below.

Innovations in Research

Researchers are seeking newer forms of treatment for early-stage prostate cancer. High-intensity focused ultrasound (HIFU) is one treatment that aims to destroy cancer cells by heating them with highly focused ultrasonic beams, much like focusing sunlight through a magnifying glass on a piece of paper. This treatment has been used in some countries for a while, but the device has just recently become available in the United States. Currently, this form of therapy is approved to ablate prostate tissue.

Drugs that block the conversion of testosterone to the more active dihydrotestosterone (DHT) are 5-alpha reductase inhibitors, such as finasteride (Proscar®) and dutasteride (Avodart®). These drugs are approved to treat prostate enlargement (BPH). They have been shown to lower the risk of prostate cancer, but are not FDA approved for that indication. These drugs are currently being studied in patients with known prostate cancer, including those on active surveillance and those with a rise in their PSA level, after prostatectomy.

One of the exciting developments in advanced prostate cancer is the introduction of several new drugs which all have different mechanisms of actions. These include several newer forms of hormone therapy. Some of these may be helpful, even if standard forms of hormone therapy are no longer working. Some examples include abiraterone (Zytiga®) and enzalutamide (Xtandi®). Other drugs include the radioisotope, Radium 223 (Xyphos®), sipuleucel-T (Provenge®), degarelix (Firmagon®) and denosumab (Prolia®).

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

Moreover, studies are now being done to see how well newer drugs, such as pembrolizumab (Keytruda®) and nivolumab (Opdivo®) target the immune checkpoint protein PD-1, might work against prostate cancer. In some other cancers, these types of drugs have been shown to shrink a larger portion of tumors.

Finally, several types of vaccines to treat prostate cancer are being tested in clinical trials.

One example is PROSTVAC, which uses a virus that has been genetically modified to contain PSA. The patient's immune system should respond to the virus and begin to recognize and destroy cancer cells containing PSA. Early results with this vaccine have been promising, and a larger study is now under way.

Prostate Cancer Clinical Trials

A vast majority of today's standard prostate cancer treatments were first shown to be effective in clinical trials. Clinical trials are not only an important step in discovering new treatments for this disease; they also carefully assess the quality of life of those who receive the treatments. When guiding men in making a decision about whether a prostate cancer clinical trial is right for them, consider the following:

- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit and possibly less side effects.
- Not all clinical trials are pharmaceutical drug trials; some may test other forms of treatment such as new surgery or radiation therapy techniques, or even alternative medicines and techniques.

To learn about current clinical trials, visit: www.clinicaltrials.gov or www.cancer.gov/about-cancer/treatment/clinical-trials
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