



Our Mission

ZERO — The End of Prostate Cancer is the leading national nonprofit with the mission to end prostate cancer. ZERO advances research, improves the lives of men and families, and inspires action. We're building Generation ZERO, the first generation of men free from prostate cancer, through our national run/walk series, education and patient support programs, and grassroots advocacy.

Who We Are

Imagine a world with zero prostate cancer deaths – we at ZERO work each and every day with that vision in mind. We are the destination for taking action to end prostate cancer and making prostate cancer a national priority. By providing educational resources, supporting scientific research, and offering patient support programs including case management, we strive to positively impact the lives of men and families fighting this disease.

A Message from Dr. Alicia Morgans



Alicia Morgans MD, M.P.H., The Feinberg School of Medicine at Northwestern University Chair - ZERO Medical Advisory Board

Dear Friends,

As we enter the holiday season, let's take a moment to remember an incredible year in progress in the fight against prostate cancer. In the past 12 months, we have seen a new therapy in apalutamide and an expanded indication for enzalutamide, both approved to prolong the time before men with non-metastatic castration-resistant prostate cancer develop spread of cancer in bones or other places after surgery or radiation.

We also learned more about the use of pembrolizumab, an immunotherapy, and olaparib, a PARP inhibitor, with abiraterone in men with metastatic castration-resistant prostate cancer, providing hope that new therapies and combinations are on their way. And we've seen ZERO reach hundreds of men in the last year through personalized and group support systems like ZERO360 and ZEROConnect, helping men feel less isolated and more empowered to seek and receive the care they need. We certainly have more to do in preventing suffering from prostate cancer, but I have hope that together we can meet the challenge and make the future brighter for it.

Wishing you and your family a brilliant new year,

Alicia Morgans

Erectile Dysfunction: What to Expect and How to Manage It

Receiving a cancer diagnosis is difficult for any man to endure. Navigating treatment options, dealing with financial strain, and facing emotional recovery are intimidating hurdles. Advanced prostate cancer survivors, and often their partners, face the additional challenge of the most common side effect of any prostate cancer treatment: erectile dysfunction (ED).

ED, also known as impotence, is when a man cannot achieve or maintain an erection for satisfactory sexual function. Most men who undergo treatment for prostate cancer will experience some ED for the

first several months after treatment, despite nerve sparing surgery or precision radiation. This is because the blood vessels that control an erection are easily affected by any trauma to the area.

Share your experience to help others. Take our online patient survey. zerocancer.org/survey ZERO THE END OF PROSTATE CANCER

Erectile Dysfunction: What to Expect and How to Manage It *(Continued from page 1)*

ED can limit your intimacy, affect self-esteem, and impact your relationship with your partner. Some men also find that prostate cancer and its treatment can cause tiredness and lack of energy, which can affect their desire for sex. It can be difficult to cope with the sexual changes, which may affect in your current or future relationships. By maintaining an open line of communication with your partner and leaning on each other for support, you can get through the challenges that come with ED. Numerous treatments are available to address ED, including physical therapy, oral medications, penile injections, vacuum erection devices, intraurethral suppositories, and penile implants.

What can I do to address my erectile dysfunction?



- Maintain a healthy diet and weight
- Stay active and exercise frequently
- Practice Kegel exercises
- Avoid drinking or smoking

As you consider treatment, it's important to keep in mind that a number of factors can impact whether you will be able to achieve an erection after treatment:

- Your ability to achieve an erection before treatment
- Other medical conditions, like obesity, high blood pressure, and diabetes
- Other medications you may be taking, including blood pressure medications
- Your lifestyle, and including whether you drink or smoke
- Your age
- The type of treatment you had
- The aggressiveness of your cancer

Talk to your doctor to determine the right ED management strategy for you. ED can be an uncomfortable topic, but being open and honest will allow your doctor to make the best treatment recommendation for you. If your doctor is not an ED expert or comfortable treating ED, you may ask for a referral for someone who is.

Managing Urinary Incontinence During and After Prostate Cancer Treatment

During primary treatment for advanced prostate cancer, most men experience some degree of urinary incontinence, or the loss of bladder control. In fact, about 25 percent of men undergoing a prostatectomy report frequent leakage or no control at six months. For the majority of prostate cancer patients, the issue will improve greatly within a year of treatment. However, others may experience urinary incontinence as a long-term side effect.

Urinary incontinence is typically caused by damage to the nerves and muscles that control urinary function during primary treatment for prostate cancer. Often, urinary frequency and urgency can go along with incontinence. The most common type of urinary incontinence among prostate cancer survivors is **stress incontinence**, the involuntary leakage of urine with an activity that puts stress on the abdomen. Patients commonly leak with activities such as laughing, coughing, sneezing, or physical strain (pushing, pulling, or lifting). **Urge incontinence**, or overactive bladder, is also prevalent among prostate cancer survivors, and occurs when you feel the urge to urinate but cannot make it to the toilet in time.

Tips for Managing Urinary Incontinence

TIPS

- Decrease your intake of drinks with alcohol and caffeine, as well as citrus juices. These beverages can irritate your bladder and make you have to go more frequently.
- Shed those extra pounds. Belly fat pushes on the bladder and can deter bladder control.
- Make a point to empty your bladder before exercising or bedtime. You can also try to empty your bladder more frequently during the day, even if you do not feel a strong urge to urinate.
- Discuss with your doctor the vitamins and supplements you take, which can have an impact on bladder control.

The good news? A number of options are available to manage and treat urinary incontinence:

- **Absorbent Products:** Undergarment solutions that can be used alone or in combination with other treatment options. Both disposable and reusable versions are available and come in the form of liners, pads, and collection devices.
- **Physical Therapy:** Kegel exercises can help strengthen the muscles that support the bladder. In addition, biofeedback/electrical stimulation can strengthen awareness and control of urinary tract muscles.
- **Medication:** Prescription medications like Flomax, Hytrin, Detrol, Myrbetriq, and Vesicare can decrease involuntary bladder contractions and improve urinary flow, control urgency, pain, and leakage. These medications generally do not work as well for stress urinary incontinence.
- **Interventional Therapies:** Collagen injections, such as Botox, add bulk to the bladder neck and provide increased resistance to prevent urine leakage.
- **Surgical Therapies:** After trying less invasive options first, surgical options include a urethral sling and/or artificial urinary sphincter.

Advance Research from Home and Earn \$50



ZERO has teamed up with Sanguine, a provider of at-home clinical research services, to give you the opportunity to help advance Metastatic Castration-Resistant Prostate Cancer (mCRPC) research from home and earn \$50 for your time. Participation in this at-home study is voluntary and requires a simple one-time blood donation. For every qualified participant, Sanguine will donate \$200 back to ZERO. **To speak with a research coordinator: call (818) 804-2463 or visit the website.**

Prostate Cancer Treatment and Memory Loss

While advanced prostate cancer patients have more treatment options than ever before, there are many side effects to consider with these treatments. Memory loss is a possible side effect of both hormone therapy and chemotherapy.

Hormone Therapy

Hormone therapy, or androgen-deprivation therapy, slows the release of testosterone and prevents it from acting on prostate cells. It is used to starve prostate cancer tumors, which require male hormones to thrive. Hormone therapy is often used before, after, and during other treatments, but it cannot cure prostate cancer. Good candidates for hormone therapy are men whose prostate cancer has moved outside their prostate, men who plan on surgery and want to shrink their tumors to bolster surgery's effectiveness, and men who have had surgery or radiation but whose prostate cancer has returned. Hormone therapy is also often used along with radiation treatment.

While hormone therapy is a key part of the treatment regimen in cases of recurrent and advanced prostate cancer, memory loss is a possible side effect. Men undergoing hormone therapy treatment often complain of memory, learning, and concentration problems. In fact, recent studies have linked hormone therapy to an increased risk of Alzheimer's disease, as low testosterone levels are known to be linked to Alzheimer's risk. If your doctor has proposed hormone therapy as a potential treatment, be sure to ask him or her about the side effect of memory loss and whether the benefits outweigh the risks for your particular case, especially if you have baseline memory problems.

Chemotherapy

Chemotherapy is a set of drugs taken either intravenously or orally by a patient whose cancer has returned after a primary treatment or has spread to other areas. Chemotherapy is used to kill cancer cells or prevent them from multiplying. Ten years ago, chemotherapy was only used to relieve symptoms associated with very advanced prostate cancer. With the emergence of Taxotere (first line chemotherapy drug), Jevtana (second line chemotherapy drug), and other chemotherapy drugs used in clinical trials, doctors now realize the survival benefits of chemotherapy for men with metastatic or advanced disease.

Chemotherapy is a very effective treatment for prostate cancer, but it has a number of side effects, one of which is often described as "chemo brain." Doctors also refer to this phenomenon as cancer treatment-related cognitive impairment, cancer-therapy associated cognitive change, or post-chemotherapy cognitive impairment. People undergoing chemotherapy often describe being in a mental fog, having trouble remembering things, multitasking, or difficulty finishing tasks, and learning new skills.

For most people, “chemo brain” only lasts a short time and subsides after finishing treatment, but others have long-term mental challenges. If you are undergoing chemotherapy and are experiencing these symptoms, be sure to tell your doctor so she or he can help you develop a plan to manage your symptoms.

Depression and Advanced Prostate Cancer Often Go Hand in Hand

Receiving an advanced prostate cancer diagnosis can be overwhelming. Once the initial shock subsides, it's common to experience feelings of worry, anger, and fear after learning about your diagnosis. A litany of questions may run through your head: What will be the side effects of my treatment? How will I cope with erection, urinary, or bowel problems? Will the role in my family change? Will I still have a sex life? Am I going to die?

In addition to the feelings that accompany an advanced prostate cancer diagnosis, prostate cancer treatment often comes with its own emotional toll. Hormone therapy can have a physical impact on your body, including weight gain, mood swings, changes to your sex drive, and reduced muscle mass and physical strength. These physical changes can result in feelings of loss and lower confidence.

With all of these changes happening at once, it's no surprise that many men living with prostate cancer experience depression. In fact, in a recent study by ZERO – The End of Prostate Cancer and Ferring Pharmaceuticals that aimed to uncover the impact of prostate cancer on patients, their caregivers, and the health care providers that support them, 64 percent of patients reported that their prostate cancer diagnosis had a moderate to severe impact on their social and emotional well-being.

Our team of experienced case managers is ready to help you and your family through your personal prostate cancer journey. ZERO360 is a free, comprehensive patient support service to help patients and their families navigate insurance and financial obstacles to cover treatment and other critical needs associated with cancer.



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

QUESTIONS FOR THE DOC



1. How can I tell whether I am just upset about my diagnosis or clinically depressed?
2. If I decide to take medication for my depression, what are the potential side effects?
3. Do you have a counselor or therapist you can recommend, perhaps one that specializes in patients with cancer?
4. What are some activities you suggest for fighting my feelings of depression?
5. What resources are available to help my family and loved ones deal with my prostate cancer diagnosis and depression?

The first step in tackling depression is recognizing the signs. While it's common to feel depressed after receiving your initial diagnosis, if weeks or months pass where you are experiencing sleep disturbances, having difficulty concentrating, feeling tired all the time, having suicidal thoughts, feeling guilty, helpless, or worthless, or not enjoying things that once gave you joy, you may be depressed. Be careful to not conflate these kinds of feelings with anxiety about your diagnosis, and do tell your doctor about them. Depression is its own illness and needs its own treatment, either through therapy, medication, or a combination of both.

In addition to working with your doctor to develop a treatment plan for your depression, you may also find comfort in joining patient support groups, where you can talk to other men living with prostate cancer who understand what you are going through. Exercise and meditation can also be great natural ways to fight depression. The key is to not hide feelings of depression or ignore them, and to develop a plan of action that will allow you to treat both conditions.

ZEROConnect

ZERO Connect is a Facebook-based, online only support group where those affected by prostate cancer can share their stories, ask questions, and connect with one another on their prostate cancer journey. It is a community of prostate cancer patients, survivors, caregivers, family members, loved ones, and friends who come together to support one another.

[Facebook.com/groups/zeroconnect](https://www.facebook.com/groups/zeroconnect)

Dispelling 6 Myths About Prostate Cancer and Chemotherapy

Some prostate cancer patients shy away from or choose not to utilize chemotherapy. Their hesitation may result from an outdated understanding of chemotherapy side effects and its effectiveness against prostate cancer.

William Oh, MD, joined us to dispel the myths surrounding chemotherapy treatment for prostate cancer so that patients understand all the options available to them.

Dr. Oh is the Deputy Director of Tisch Cancer Institute as well as its Chief of the Division of Hematology and Medical Oncology. He is also a Professor of Medicine at the Icahn School of Medicine at Mount Sinai.

Let's explore the myths driven by common misperceptions about chemotherapy and find out the facts.

MYTH #1: Chemotherapy is a last resort.

Some patients believe that we use chemotherapy when we are out of options. Far from a last resort, there are currently promising studies utilizing chemotherapy earlier in the treatment of prostate cancer. For instance, in men with newly diagnosed metastatic disease, chemotherapy significantly improves survival.

MYTH #2: Chemotherapy is a single and outdated option.

Chemotherapy is not a single drug. In fact there are many "chemotherapies", both oral and intravenous, and new chemotherapies are being developed and approved regularly.

In prostate cancer, there have been continuous improvements over the past few years. In the past, an older drug called mitoxantrone was approved by the FDA to relieve cancer symptoms only. Then something important happened in 2004: docetaxel chemotherapy was shown to be the first drug to improve overall survival for men with metastatic prostate cancer that became resistant to hormone treatments. This was a critical milestone, as no drugs to that point could lengthen survival. In 2010, the FDA approved another chemotherapy drug for prostate cancer called cabazitaxel.



Far from being outdated, these advancements allow me as an oncologist to have a larger toolbox to treat cancers which adapt to different types of treatments.

For instance, resistance often develops to drugs like abiraterone or enzalutamide, which target the androgen receptor. Chemotherapy may more effectively kill those resistant cancer cells.

Finally, ongoing research will determine how best to combine chemotherapy with other drugs and radiation as well as use biomarkers to personalize treatment. We thought chemo might go away with newer treatments, but we use it as often as we did before as men are living longer and better lives with advanced prostate cancer.

MYTH #3: Chemotherapy has no role in an era of immunotherapy and precision medicine.

Some people believe chemotherapy is a 'shotgun' approach. Patients want more targeted therapy specific to their cancer. The fact is we do have specific chemotherapy to kill prostate cancer cells called taxanes. Taxanes stop cancer cells from dividing and also may interfere with androgen receptor signaling in prostate cells as well.

In fact, when a patient stops responding to drugs such as abiraterone or enzalutamide, a blood test for a biomarker called ARV-7 predicts greater benefit from chemotherapy than continuing the androgen pathway drug. This test is now approved in the U.S.

MYTH #4: I'll be nauseated and vomiting throughout my chemotherapy.

Chemotherapy induced nausea and vomiting (CINV) can be very scary and intimidating and many patients have known or heard about someone who has had it. Two things are really important to understand about CINV.

First, there are many types of chemotherapy and their ability to cause CINV varies widely. In fact the drugs used in prostate cancer are unlikely to cause this. The American Society of Clinical Oncology (ASCO) Guidelines consider cabazitaxel, for instance, as a "low risk" drug for causing CINV.

Second, modern antiemetics have revolutionized the treatment of CINV. Antiemetics are drugs used to prevent nausea and vomiting and there are a host of agents available to use. Typically I will incorporate one of these on the day of therapy and prescribe something for home, but most patients do not need it.

MYTH #5: I won't be able to function day-to-day while on chemo.

Some men believe their quality of life will drastically suffer while on chemotherapy. Fortunately, these newer drugs have much fewer side effects. The most common side effect in day-to-day life is fatigue. This is usually mild to moderate and I find that most patients are able to continue many of their regular activities. For instance, they may continue to work, spend time with family, and exercise.

MYTH #6: I'll permanently lose all my hair after chemo.

It is true that many prostate cancer patients experience temporary hair loss while undergoing chemotherapy. Some patients won't lose their hair at all. Others will experience thinning hair.

In nearly all patients, the hair loss is reversible once chemotherapy is complete. If you experience hair loss, your hair should grow back several months following your chemotherapy treatment.

FACT: Chemotherapy is a key treatment in the fight against advanced prostate cancer.

Battling prostate cancer may be the hardest fight you've encountered. Certainly, the side effects of some of the treatments you've received have been difficult. There is no question that chemotherapy comes with its own set of challenges.

However, it is critical to understand how important chemotherapies used to combat prostate cancer can be in extending and even improving your life. Many studies have shown that drugs such as docetaxel, cabazitaxel, and others can play a key role in treating metastatic prostate cancer, cancer that has spread beyond the prostate.

Please ask your oncology team about any specific concerns you may have before starting any treatment regimen. Knowledge is the most effective tool in the battle against prostate cancer.



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