

MY PROSTATE CANCER ROADMAP

UNDERSTANDING YOUR ROAD

You already know about prostate cancer. Now it's time to talk about living with [advanced prostate cancer](#). Being diagnosed with advanced prostate cancer can stop you in your tracks. You have questions. And these are important questions. You want to know "How bad is it? [What are my options?](#) [What does this mean for my life and everyone in it?](#)" Explore the site to learn more about these topics, but start by understanding the road you are on.

"We are the same men, but different: we are fundamentally, emotionally and spiritually moved by our experiences. We are making a journey that was not our choice, but on a path that we have chosen for ourselves, and we have a perspective unique to us as individual men."

ALAN W.

WHAT ARE THE STAGES OF PROSTATE CANCER?

Not all prostate cancer is the same. It ranges from cancer confined to the prostate gland to cancer that has spread outside of the prostate to the lymph nodes, bones, or other parts of the body. You can determine the extent or spread of the cancer by knowing the stages of prostate cancer:

STAGING DETERMINES THE EXTENT, OR SPREAD, OF PROSTATE CANCER

STAGE I

The tumor is confined to the prostate.

STAGE II

The tumor is more advanced than Stage I, but doesn't extend beyond the prostate.

STAGE III

The tumor extends beyond the prostate and may have invaded the seminal vesicles (tubular glands above the prostate), but cancer cells have not spread to the lymph nodes.

STAGE IV

The tumor may have invaded the bladder, rectum or nearby structures (beyond the seminal vesicles) and may have spread to the lymph nodes, bone or to other parts of the body.

Stages III and IV are considered to be advanced prostate cancer. Stage III is also known as "locally advanced" and Stage IV as "metastatic" prostate cancer.

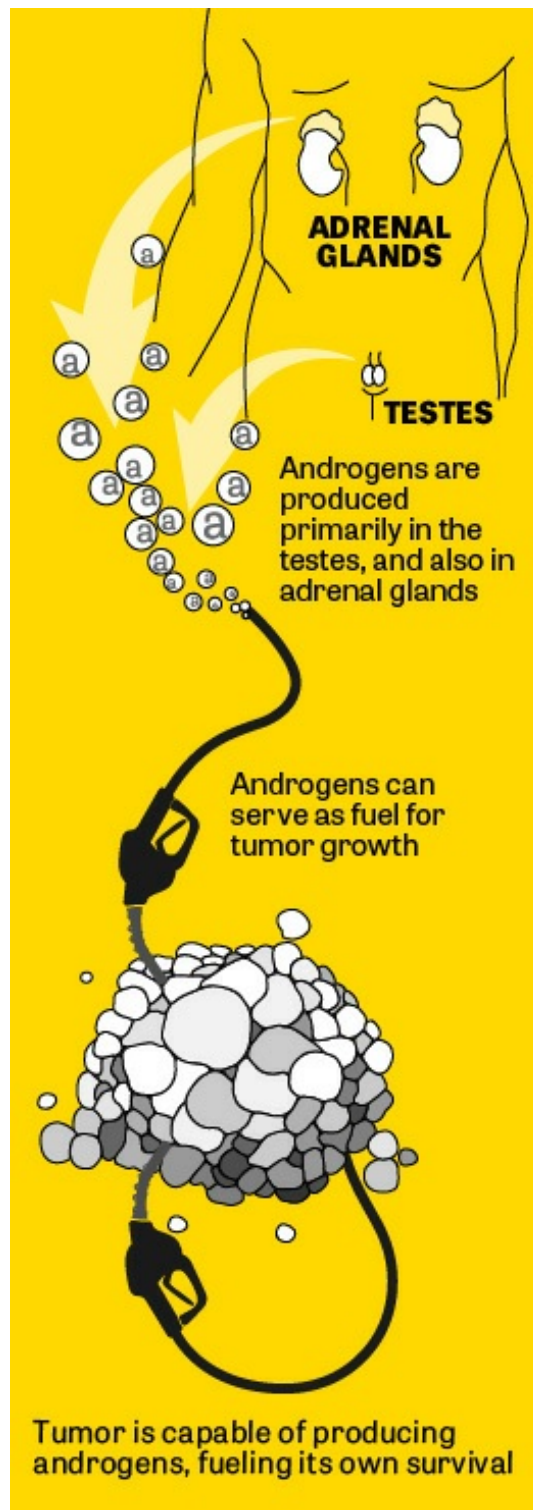
There are multiple types of advanced prostate cancer, including:

- **Locally Advanced:** Cancer that has grown to fill the prostate or has grown through the prostate and may extend into the glands that help produce semen (seminal vesicles) or the lymph nodes.
- **Biochemically Recurrent (Rising PSA):** Patients who have a rising [prostate-specific androgen \(PSA\)](#) after treatment, but do not show any evidence that the disease has spread to bone or other organs. This can occur after local treatment or after hormone therapy.
- **Metastatic (Hormone-Sensitive):** Cancer that has spread (metastasized) to the bone, lymph nodes or other parts of the body.
- **Castration-Resistant Prostate Cancer (CRPC):** CRPC is prostate cancer that continues to grow despite the suppression of male hormones that help fuel the growth of prostate cancer cells.
- **Metastatic Castration-Resistant Prostate Cancer (mCRPC):** mCRPC is a form of advanced prostate cancer where the cancer has spread to parts of the body other than the prostate, and it is able to grow and spread even though drugs or other treatments to lower testosterone are being used to manage the cancer. That is, the cancer has the ability to thrive in a low testosterone environment.

Patients who have been treated for prostate cancer in the past will likely attend regular checkups. Your doctor will watch for any increases in your PSA level and the speed with which any increases occur. A higher PSA does not necessarily mean your cancer has come back. But it may mean that you need further tests, such as other imaging tests to help your doctor determine if the cancer has spread.

To find more information and resources on screening, we recommend visiting [About Screening](#) from the Prostate Conditions Education Council (PCEC).

WHAT'S FUELING THE CANCER?



If you have mCRPC, your tumor may be fueled by [androgens](#). Androgens are hormones – primarily produced in the testes, and also made in the [adrenal glands](#) – that contribute to male characteristics, like your baritone voice, muscle tone and facial hair. However, for men with mCRPC, androgens can play a negative role by helping to fuel tumor survival.

Research has shown that tumors are capable of producing their own additional androgen to help fuel themselves. Some mCRPC treatments attempt to slow or stop production of the hormones, basically depriving the tumor of the androgens fueling it.

HOW IS PROSTATE CANCER DIAGNOSED?

Most prostate cancers are first found during screening with a PSA blood test and/or a digital rectal exam (DRE). Early prostate cancers usually don't cause symptoms, but more advanced forms may be found because of symptoms they

cause. Whether prostate cancer is suspected based on screening tests or the presence of symptoms, the actual diagnosis is made with a biopsy of the prostate.

A pathologist studies prostate tissue samples collected during a biopsy under a microscope to determine the grade of the tumor (i.e., how different the tumor tissue is from normal prostate tissue).

Sometimes primary cancer is discovered only after the metastatic tumor begins to cause symptoms. For example, if your prostate cancer has spread to the bones in your pelvis, you may have lower back pain. Although not common, this may happen before you experience any symptoms from the primary tumor in your prostate.

WHAT ARE PROSTATE CANCER RISK FACTORS?

Older men are more likely to develop prostate cancer, as the chance of having prostate cancer rises rapidly after age 50. About six in 10 cases of prostate cancer are found in men over the age of 65.

Family history may be a risk factor. If your father or brother has had prostate cancer, you are about twice as likely to develop this disease compared to a man with no family history of the disease. The risk is even higher for men with several relatives who have or had prostate cancer.

While reasons are unknown, race also plays a role in who is at risk for prostate cancer. African-American men are 1.6 times more likely to get prostate cancer than Caucasian men. Prostate cancer occurs less often in Asian-American and Hispanic/Latino men than in non-Hispanic Caucasian men.

RISK FACTORS

- **AGE 50 OR OLDER**
- **FAMILY HISTORY**
Father or brother has had prostate cancer
- **RACE/ETHNICITY**
African-Americans are at higher risk than Caucasians and Hispanics. Prostate cancer occurs less often in Asian-American and Hispanic/Latino men than in non-Hispanic Caucasian men
- **PRE-CANCEROUS PROSTATE CHANGES CAN BE A PRECURSOR TO CANCER**
- **GENETIC (CHROMOSOMAL) ABNORMALITIES**
Such as a certain altered or missing gene

MEETING YOUR HEALTH CARE TEAM

In this video, Rob discusses his personal experience in working with his healthcare team to navigate approaches to prostate cancer.

YOU + YOUR TEAM

When you are diagnosed with advanced prostate cancer, it can be stressful – even overwhelming at times. You do not have to face this alone. In fact, you should not face it alone. Friends and family want to help, but may feel uncomfortable

offering assistance at the risk of intruding. Let them know you welcome their support in building your own cancer support community. It can be invaluable on your journey.

Other important resources are available, and may include:

- **Oncology social workers** provide emotional support for you and your loved ones when the going gets tough. These professionals can be found through organizations like [CancerCare](#) and can help you cope with the challenges of living with advanced prostate cancer and guide you to resources.
- **Support groups**, both in-person and online, allow you to share your concerns with other men going through the same experience and provide insights and practical suggestions on ways to manage your situation. One resource for support groups can be found through the [Us TOO International Prostate Cancer Education and Support Network](#).
- **Advocacy groups** help patients, their families and their caregivers navigate the cancer landscape. These groups work to ensure cancer patients receive appropriate and timely care, education and financial assistance, when needed. One resource is the [Advocacy Connector](#), which helps connect patients and caregivers with advocacy resources and groups specific to their needs.
- **Financial help** is offered by a number of organizations to help cover cancer-related costs, such as transportation to treatment, or help needed around the home. [CancerCare](#) provides referrals to organizations that provide assistance.



YOU + MEDICAL TEAM

[Advanced prostate cancer](#) is a complex disease that varies from patient to patient. Treatment plans are complex and may also vary depending on the specifics of your situation. For this reason, one doctor may not be able to provide all the information and expertise required for you to battle this disease. You may need a team of medical experts to help you manage your condition. Members of your medical team may include some or all of the following:

- **Urologist:** A doctor who specializes in diseases of the urinary and sex organs.
- **Urologic oncologist:** A doctor who diagnoses and treats cancers of the genitourinary system.
- **Medical oncologist:** A doctor who is trained in the diagnosis and treatment of cancer and specializes in the use of chemotherapy and other drugs to treat cancer.
- **Radiation oncologist:** A doctor who specializes in using radiation to treat cancer.
- **Oncology and Urology Nurses:** Nurses who work with their respective specialists. For example, a nurse can play a critical role by monitoring side effects from your treatments and reporting them to your doctor.

Rob on the benefits of connecting with others experiencing prostate cancer through support groups.





YOUR ROLE

It is important to remember that, as the patient, this is your journey and you are in the driver's seat. It is your role to decide what is most important to you about your care. Don't be afraid or reluctant to ask questions of your medical team or other experts regarding your diagnosis or treatment plan. A second medical opinion may provide more information on a treatment that you are considering or one that you have not yet considered. Be persistent in your search for answers. Be vocal about how you're feeling and what you need to feel more at ease. The best offense is a good defense, and a good defense is to be informed.

Talking about your journey may not be second nature to you, but it's a critical part of managing your disease. Communicate with your loved ones, too. Keeping them informed of your treatment journey can help them better cope with the emotional impact your condition may have on them. By keeping your loved ones fully informed about your condition, they can be more emotionally ready to support you as your condition progresses.

DEFINING TERMS: GLOSSARY

Taking control is easier when you know the details. Learn some common medical terms that will help you navigate your advanced prostate cancer journey. You will see these terms throughout the site and you may have already heard them from your health care team, so get familiar with them.

ACTIVE SURVEILLANCE

May be a treatment option for some men with certain types of prostate cancer only. Involves careful monitoring for signs that the disease has advanced and includes: periodic prostate-specific antigen (PSA) tests, digital rectal examination (DRE) tests and other tests, such as routine biopsies. If signs of disease progression are present, active treatment might be started.

ADRENAL GLANDS

Glands that sit on top of the kidneys that produce steroids and hormones, including five to 10 percent of a man's testosterone.

ADVANCED PROSTATE CANCER

Cancer that has moved beyond the prostate region to the lymph nodes, bone or other parts of the body.

ANDROGEN

Category of sex hormones that promote the development and maintenance of male sex characteristics.

ANDROGEN DEPRIVATION THERAPY (ADT)

Treatment to suppress or block the production or action of male hormones.

ANTIANDROGENS

Drugs that block the action of androgens.

BRACHYTHERAPY (INTERNAL RADIATION)

Placement of tiny radioactive “seeds” inside the prostate to attack the cancer.

CASTRATE LEVEL

Occurs when the level of a man’s testosterone drops due to surgical or chemical (drug) therapy.

CHEMOTHERAPY

Type of drug(s) that kill cancer cells.

DIGITAL RECTAL EXAMINATION (DRE)

Insertion of a lubricated, gloved finger into the rectum by a physician to check for hard or lumpy areas in the prostate through the rectal wall.

EXTERNAL BEAM RADIATION

Prostate cancer treatment in which radiation is focused on the prostate gland from a source outside the body.

GLEASON SCORE

A scale from 2-10 that describes how closely the cancer cells resemble normal, healthy cells. In general, cancers with lower Gleason scores (2-4) tend to be less aggressive while cancers with higher Gleason scores (7-10) tend to be more aggressive. Cancers with intermediate Gleason scores (5-6) fall somewhere in the middle.

IMMUNOTHERAPY

Treatment to boost or restore the ability of the immune system to fight cancer, infections and other diseases.

INVESTIGATIONAL TREATMENT

Treatment that is still being evaluated through clinical trials and not yet approved by the U.S. Food and Drug Administration (FDA).

METASTATIC CASTRATION-RESISTANT PROSTATE CANCER (mCRPC)

mCRPC is cancer that has spread to parts of the body other than the prostate, and it is able to progress and spread even though drugs or other treatments to lower the amount of male sex hormones are being used to manage the cancer.

ORCHIECTOMY

Surgical removal of the testicles to stop or decrease the body's production of testosterone, a hormone that can help feed prostate cancer growth.

PELVIC LYMPH NODE DISSECTION

Surgery to remove lymph nodes in the pelvis for examination under a microscope to see if they contain cancer. Lymph nodes are small structures that work as filters for harmful substances, but can also collect fluid, waste material and substances that are in the body tissues.

PROSTATE-SPECIFIC ANTIGEN (PSA) TEST

Measures the level of PSA, a protein produced by prostate gland cells, in the blood. Used as a screening tool, as prostate cancer or benign (non-cancerous) conditions can also increase a PSA level.

RADIATION THERAPY

Use of high-energy rays or particles to kill cancer cells. The two main types of radiation therapy are external beam radiation and brachytherapy (internal radiation).

RADICAL PROSTATECTOMY

Surgery to remove the entire prostate gland plus some surrounding tissue to remove the cancer.

RECURRENCE RISK

The risk of the return of cancer after treatment and after a period of time during which the cancer cannot be detected.

SALVAGE THERAPY

Treatment that is given after the cancer has not responded to other treatments.

TRANSRECTAL BIOPSY

The most common way of performing a prostate biopsy, a transrectal biopsy is performed by passing the needle through the wall of the rectum to collect tissue samples from the prostate.

TRANSRECTAL ULTRASOUND

Your doctor will insert a thin ultrasound probe into your rectum to create images of your prostate. Sound waves guide the prostate biopsy needle into place and help your doctor target suspicious areas.

CHOOSING YOUR ROAD

TREATMENT DECISION FACTORS

So you have been diagnosed with [advanced prostate cancer](#), and it's up to you and your physician to decide how to treat and manage it. Take control; today is the day to talk to your doctor about your advanced prostate cancer treatment options.

Your physician or health care team takes many factors into consideration when recommending your individualized treatment plan for advanced prostate cancer. These can include your age, additional health risks, extent and stage of your cancer and the potential side effects of various treatments. Some options are specific to the type of advanced disease, including [radiation therapy](#), [hormone therapy \(androgen deprivation therapy/ADT\)](#), secondary hormonal therapy, [immunotherapy](#), [chemotherapy](#) and radiopharmaceutical therapy.

Learn as much as possible about the treatment options available and, in conjunction with your health care team, make a decision about what is best for you. Consider – and talk to your doctor, nurse and loved ones about – what you want to be able to do while on treatment.

SOME OF YOUR DECISION FACTORS MAY INCLUDE:

- MEDICAL HISTORY AND PROGNOSIS
- YOUR PERSONAL FINANCIAL SITUATION
- YOUR DESIRE FOR A CERTAIN THERAPY BASED ON RISKS, BENEFITS AND YOUR LIFESTYLE

Take the time needed to make thoughtful and informed decisions. Consultation with a prostate cancer specialist, such as a urologist, a radiation oncologist or a medical oncologist, will give you a comprehensive assessment of the available treatments and expected outcomes. Many hospitals and universities have multidisciplinary prostate cancer clinics that can provide one or more of these consultation services.

CHANGING COURSE

Every patient's treatment plan and journey is unique, so you may need to shift treatment strategies over the course of your disease. This is a normal part of your journey, so feel empowered to make those course-changing decisions with your physician that align with your desires in life.



Your doctor can help you learn more about several available treatment options and the sequence of treatment (i.e., receiving one treatment before or after another) that may be the best for your personal situation. It's important to consult regularly with your doctor regarding the treatment you're on and any other treatment options you may be considering. Your health care team is also an excellent resource to seek out should you have more questions about choosing a treatment course that is right for you.

EVALUATING YOUR OPTIONS

Here Rob discusses different treatment options and how to be a driver of your own treatment plan, with the support of your healthcare team.

You have many treatment choices. Learning about advanced prostate cancer treatment options will help you make the right decisions for you. Become informed.

TAKE CONTROL BY:

→ ASKING QUESTIONS

- DOING YOUR OWN RESEARCH
- SEEKING A SECOND OPINION
- FINDING OUT HOW DIFFERENT TREATMENTS CAN AFFECT YOUR HEALTH AND LIFE
- KNOWING YOU CAN MAKE HEALTH DECISIONS THAT ALIGN WITH YOUR LIFESTYLE

Knowing your health status is also important for discussions with your health care team. The Prostate Conditions Education Council (PCEC) provides the “Know Your Numbers Tracker Card,” which is a very helpful wallet size card that allows you to track multiple test results over an extended period of time. Find out how to receive the [“Know Your Numbers Tracker Card.”](#)

This is your life. Make the choices that are right for you.

TREATMENT OPTIONS FOR PROSTATE CANCER

EARLY STAGE PROSTATE CANCER

MINIMALLY-INVASIVE PROCEDURES

A minimally-invasive procedure such as robotic/laparoscopic surgery, cryosurgery, transurethral resection surgery, or high-intensity focused ultrasound (HIFU) may be an option.

SURGERY (EARLY-STAGE TREATMENT OPTION)

Surgical removal of the prostate is an option for some men.

SURGICAL OPTIONS INCLUDE:

- Radical Prostatectomy – Involves removing the entire prostate and some surrounding tissue
- Cryosurgery – Freezes and destroys prostate tissue and may be useful for men with early-stage prostate cancer who cannot have a radical prostatectomy

ACTIVE SURVEILLANCE (EARLY-STAGE MONITORING OPTION)

“Watchful waiting” approach to early-stage, slowly growing prostate cancer.

- May be considered for patients whose risk factors for treatment are worse than the benefits of therapy
- Physician puts off treatment until monitoring shows that the prostate cancer is growing or changing

When cancer progresses, other treatment options are considered.

ADVANCED-STAGE PROSTATE CANCER

HORMONAL THERAPY (LATER-STAGE TREATMENT OPTION)

Works by reducing the effect of androgens in one of these ways:

- Drugs that block the action of androgen
- Drugs that interrupt the androgen-making process
- Orchiectomy – Surgical removal of the testicles

ADT is the main treatment for tumors that have already recurred or spread.

ANDROGEN PATHWAY TREATMENTS (LATER-STAGE TREATMENT OPTION)

- Advanced prostate cancer that has stopped responding to ADT may require additional treatments
- Androgen-receptor blockers prevent androgens from binding to the surface of prostate cancer cells
- Hormone therapy that reduces the production of testosterone / androgens at multiple sources

IMMUNOTHERAPY (LATER-STAGE TREATMENT OPTION)

Stimulates the body's immune system to help it recognize and fight off cancer cells.

- Involves removing some of the patient's white blood cells, separating out the immune cells, and returning modified immune cells back to the patient
- May be used for men with advanced prostate cancer that is resistant to ADT (medical or surgical treatments that lower testosterone)

CHEMOTHERAPY (LATER-STAGE TREATMENT OPTION)

Uses medication to kill cancer cells.

- Chemotherapy may be used for men with advanced prostate cancer that has progressed on conventional ADT.

RADIATION THERAPY (LATER-STAGE TREATMENT OPTION)

Uses high-energy radiation to kill cancer cells.

- External Beam Radiation – Given from a machine outside the body
- Brachytherapy – Radioactive seeds are placed in and around the tumor

RADIOPHARMACEUTICALS (LATER-STAGE TREATMENT OPTION)

Uses drugs with radioactive elements to treat cancer that has moved to bone.

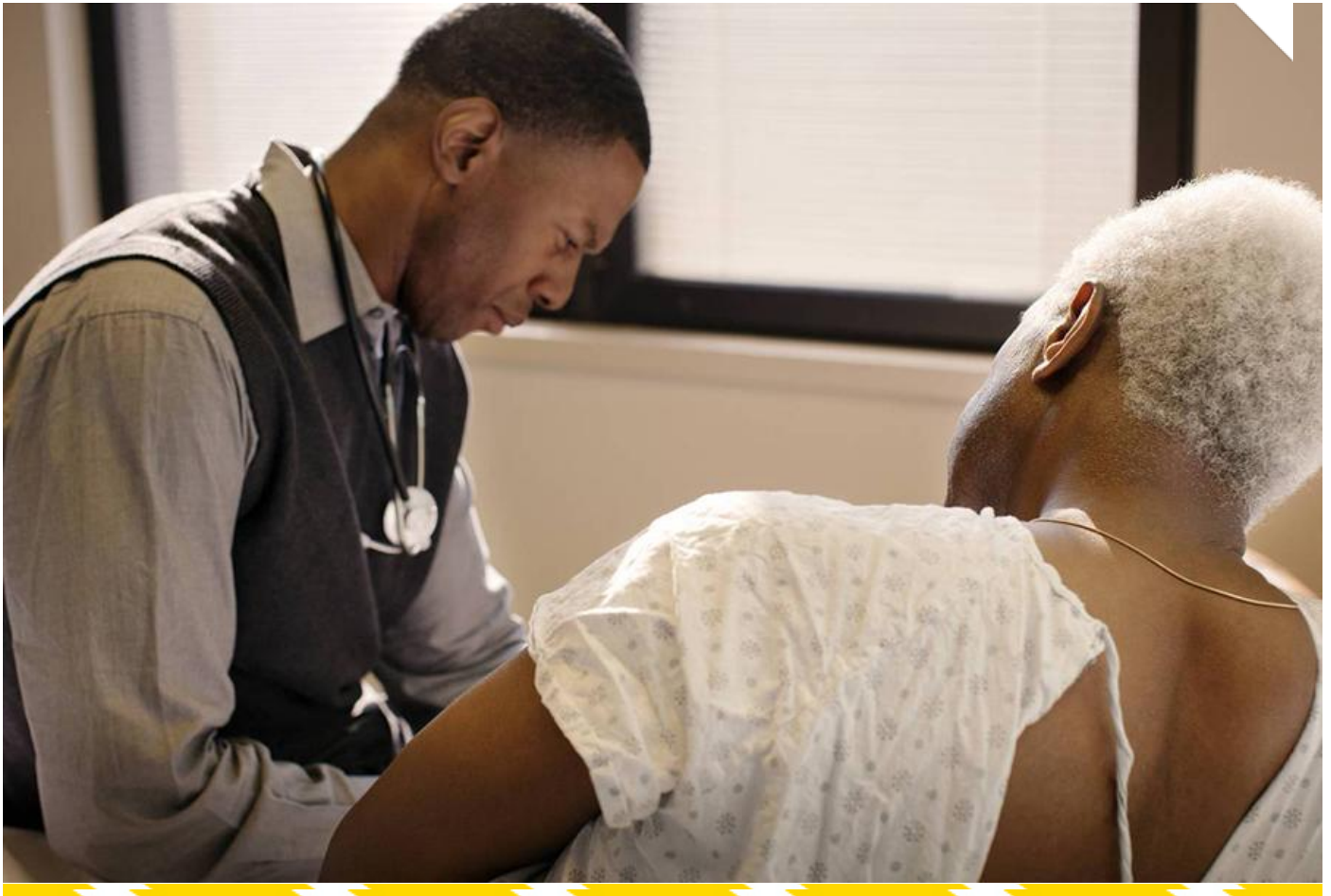
- Sometimes combined with external beam radiation
- Has been shown to help with pain of cancer in bone
- Drugs are injected into a vein and then settle in areas of bone where cells turn over

TALKING WITH YOUR DOCTOR ABOUT TREATMENT

If your PSA is rising, the cancer has returned or spread or is no longer responding to treatment, your disease may be progressing. But how much do you really know about what is happening within your body? With your initial diagnosis, your doctor used a number of tools and tests to choose the most appropriate treatment option, weighing the risks of side effects and the probability of successfully treating the cancer. This is also true when you experience a recurrence or the

cancer is not responding to treatment. You may have many pressing questions at this time, such as:

- Why is the treatment not working?
- What does this mean?
- What options do I have?



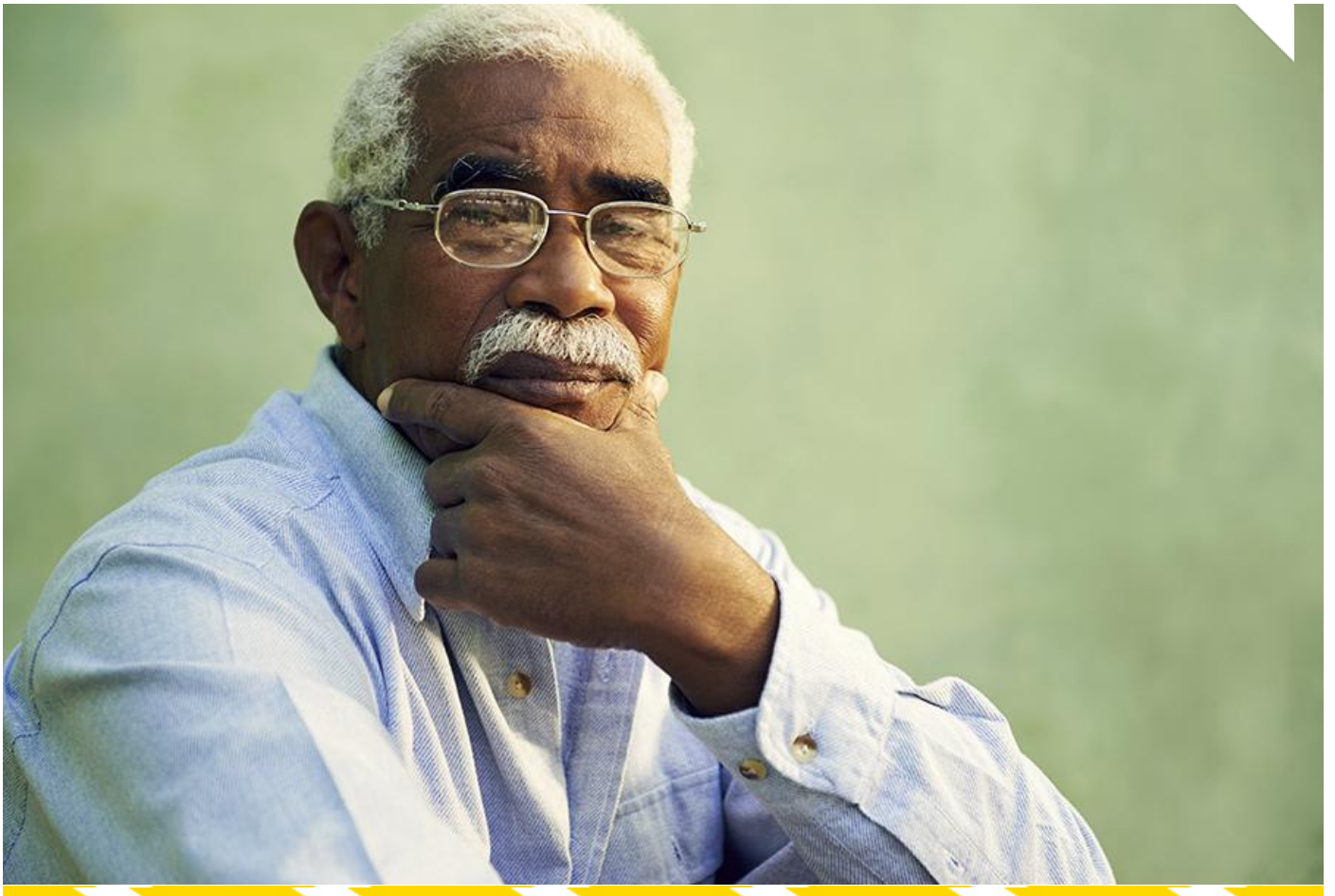
Your health care team has the answers – it's up to you to ask the questions.

Being diagnosed and going through treatment for [advanced prostate cancer](#) is stressful and may be one of the biggest challenges you face in your life. It is normal to feel anger, sadness, fear or frustration. Depression is a real issue for many men facing prostate cancer. It can be brought on by many factors, and can also be a result of the side effects of your treatment. Do not shrug it off. Talk with your loved ones and health care team if you think you are depressed and determine how to tackle it. There are also various advocacy groups featured on [The Road Together](#) page, which provide resources to deal with these feelings.

Most importantly, know that you have [options](#). Please discuss with your doctor which options are right for you.

EXPLORING CLINICAL TRIALS

There are many advanced prostate cancer clinical trials currently being conducted to test new treatments. Clinical trials are organized studies conducted in patients to evaluate a drug's safety and efficacy. They are required by the U.S. Food and Drug Administration (FDA) before a particular treatment can be made available to the public.



Clinical trials can:

- Answer specific questions about new treatments
- Test new ways of using established treatments
- Test the safety and effectiveness of a treatment

Every clinical trial is designed to answer a specific set of questions about a treatment. Each study enrolls patients with certain types and stages of cancer and a defined health status. If you fit the criteria for a clinical trial, you may be eligible to take part.

Your doctor may not always be aware of a study that you could join, so you should check out [ClinicalTrials.gov](https://clinicaltrials.gov) to find out if one is available or the [Us TOO Clinical Trials page](#) to learn more about resources around clinical trials and the types of trials out there. If you find an appropriate study, you must have a reasonable understanding of the possible risks and benefits and be freely willing to take part in it. All patients in clinical trials are carefully monitored during and after participating in the trial.

KNOWING YOUR FINANCIAL RESOURCES

There are costs including and beyond treatment options that you may not have planned for. The financial impact of a cancer diagnosis does not have to be a major source of stress and anxiety for you.



It can be difficult to discuss the cost of cancer treatment, but it's important to address. Talking about costs will not make your health care team see you as bothersome or cause them to delay treatment or offer a less effective treatment. They will be able to help you understand what to expect and, if needed, seek assistance.

With everything else going on, consider asking someone you trust to help manage this aspect of care for you since it can be daunting.

ADVOCACY GROUPS AND FOUNDATIONS

It is important to know there are resources and support available to help with many costs associated with a cancer diagnosis. There are many resources dedicated to patient support for medication costs, such as:

CANCERCARE

www.cancercare.org

1-800-813-4673

PATIENT ACCESS NETWORK FOUNDATION

www.panfoundation.org

1-866-316-7263

PATIENT ADVOCATE FOUNDATION

www.patientadvocate.org

1-800-532-5274

CANCER FINANCIAL ASSISTANCE COALITION (CFAC)

www.cancerfac.org

CANCER.NET'S PATIENT GUIDE, "MANAGING THE COST OF CANCER CARE"

www.cancer.net

1-888-651-3038

GOVERNMENT RESOURCES*

Treatments can also be covered by different types of Medicare plans. Patients requiring financial assistance may be eligible for a variety of cost-support options, including:

MEDICARE EXTRA HELP

Low income subsidy

- Helps pay premium, deductible, co-insurance and co-payment costs for patients on Medicare Part D for those with limited resources and income
- Eligibility is based on income; patients qualifying for Extra Help may pay less than \$7 per prescription

MEDICARE SAVINGS PROGRAM

Qualified Medicare beneficiary

- For eligible patients, this program helps pay for Medicare Part A and B deductibles and premiums
- Patients who qualify for the savings program are automatically eligible for Extra Help, which helps with prescription co-pays

STATE PHARMACEUTICAL ASSISTANCE PROGRAMS (SPAPs)**

- May be able to help pay premiums and/or drug costs for eligible medical conditions
- Programs vary by state and may not be available in every area

For more information about these programs, visit www.medicare.gov.

U.S. DEPARTMENT OF VETERANS AFFAIRS (VA)



Veterans with prostate cancer may be eligible for U.S. Department of Veterans Affairs (VA) benefits, including health care and disability compensation. To get more information on veteran services and resources, download this [Veteran's Guide brochure](#).

PHARMACEUTICAL MANUFACTURERS

Individual manufacturers may make medication co-pay assistance programs available to you if you have commercial insurance and meet other eligibility criteria. These programs offer support through various options, including:

- Assessing your insurance benefits to help you understand any potential out-of-pocket expenses
- Providing information on cost support options, such as instant savings programs or patient assistance programs, as appropriate
- Providing additional support, such as ongoing cost support status updates, prescription reminders and educational materials
- Coordinating with your local pharmacy or specialty pharmacy to arrange for efficient prescription pick-up or drop-off

For more information about individual manufacturer assistance programs, talk to your physician or connect with an advocacy group via the [Advocacy Connector](#).

INDEPENDENT FOUNDATIONS AND ORGANIZATIONS*

CHRONIC DISEASE FUND (CDF)

- Co-pay assistance for FDA-approved specialty medications
- Funds are available for specific disease states that may have different eligibility guidelines
- Find out the current status of funds and more information at www.cdfund.org

THE PATIENT ADVOCATE FOUNDATION (PAF) CO-PAY RELIEF (CPR) PROGRAM

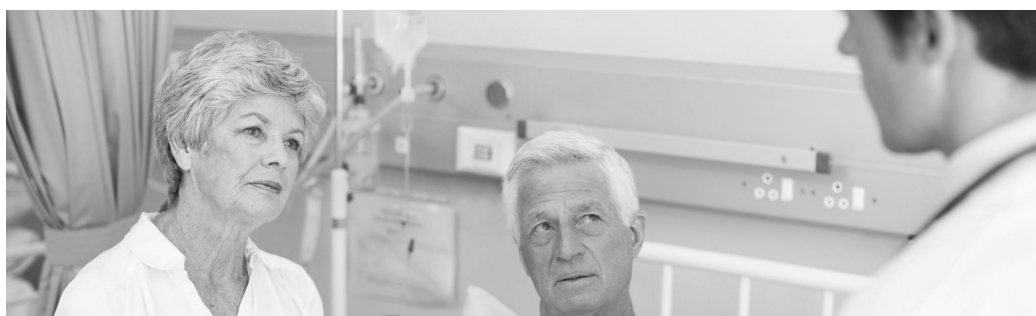
- Helps with co-payments, co-insurance and deductibles
- Eligibility is based on income
- Find out the current status of funds and more information at www.copays.org

CANCERCARE CO-PAYMENT ASSISTANCE FOUNDATION (CCAF)

- Member of Cancer Financial Assistance Coalition (CFAC)
- Helps cancer patients afford co-payments for chemotherapy and targeted drugs
- Find out the current status of funds and more information at www.cancercarecopay.org

* The information provided represents no statement, promise or guarantee by Janssen Biotech, Inc. concerning levels of reimbursement, payment or charge. Please consult your payer organization with regard to local or actual coverage, reimbursement policies and determination processes. Information is subject to change without notice. Nothing herein may be construed as an endorsement, approval, recommendation, representation, or warranty of any kind by any plan or insurer referenced herein.

** SPAPs are not limited to Medicare Part D. Note that not every SPAP is a Medicare Part D participant.





PLANNING FOR EXPENSES

Take some time to prepare a budget and determine what support you might need. Your personal costs will depend on several factors, including the type of advanced prostate cancer treatment you choose and your health insurance coverage. Many cancer support groups offer financial counseling and advice on coping with the stresses that come with the financial burden. A good place to start is the [CancerCare](#) helpline: 800 813 HOPE (4673).

Some costs might be more obvious than others. Below are some costs to consider:

DOCTOR'S APPOINTMENTS

If you have a co-pay for each visit to the doctor and your visits to the doctor increase, your co-payments may add up. Lab tests and radiology tests may require separate payment. If you find you cannot manage your frequent or costly appointment co-pays, talk to your physician and their office may consider waiving the costs of some of your co-pays.

TREATMENTS AND PROCEDURES

There may be costs for procedures and other treatments. Certain treatments, like radiation therapy, require daily visits for a set time period. While you most likely will not have a co-pay for each visit, you may be responsible for a portion of the total cost with a fee, such as co-insurance. If you are continuing to work through treatment, consider the time away from your job and the potential impact on your paycheck.

MEDICATIONS

Many advanced prostate cancer treatments can come with out-of-pocket co-payments. Fortunately, there are many resources available, such as the [ZERO-PAN Co-Pay Assistance Program](#) that can help to offset these costs. Talk with your health care team so you can anticipate costs and how you will manage these new costs. Many pharmaceutical companies are committed to providing access to medicines for uninsured patients who lack the financial resources to pay for certain donated medicines, so be sure to check websites for medications prescribed to you for such resources.

LIVING EXPENSES

Added expenses like co-pays and out-of-pocket items begin to add up, and this can impact the activities you normally do. Consider how much your regular living expenses will be impacted by the cost of treatment.

TRANSPORTATION AND TRAVEL

Consider the expenses for traveling to and from the doctor's office. Factor in the cost of gas and, if applicable, parking. Depending on where you decide to receive treatment, you may also need to pay for lodging away from home.

EMPLOYMENT, LEGAL AND FINANCIAL ISSUES

These costs may arise if you need professional guidance on employment, legal or financial issues related to your prostate cancer diagnosis. This may involve addressing loss of wages, learning about employment rights under the law, figuring out medical expenses during income tax filing, or writing a will. For making decisions after a loved one has passed away, the American Cancer Society provides [financial guidance for coping with the loss of a loved one](#).

CAREGIVING, AT-HOME CARE AND LONG-TERM CARE

No one wants to talk about it, but you may find that at some point you need extra help at home. A person

can be hired to prepare meals, drive you to medical appointments or assist with personal care.

Thinking about all of these potential costs may make you feel anxious about the future. However, local and national financial resources or a representative from your doctor's office and/or health insurance provider can help you better understand these costs. Again, the CancerCare helpline (800 813 4673) is a great place to start the conversation.

NAVIGATING YOUR ROAD

Living with [advanced prostate cancer](#) will impact your relationships and your daily routines. Part of living with this disease is understanding how it will change your relationships, your health and your daily activities, and then beginning to proactively take control.

Of course, side effects such as fatigue or sleep problems can make it difficult to find the motivation and energy to be active. Certain treatments can worsen these side effects, so if you are experiencing fatigue or other side effects, make sure to alert your doctor or nurse.

Beyond side effects, make sure your doctor or nurse is aware whether or not you feel like yourself while on your prescribed medication – side effects are one thing, but your health care team also wants to know how your condition and treatment regimen are affecting your everyday life.

STAYING ACTIVE

You may not feel like staying active, but physical activity and exercise can help in fighting the disease and staying as healthy as possible. Walking, gardening, playing golf or playing with your grandkids are just a few ways to stay active. Talk to your doctor about what activities or forms of exercise are right for you.

The following forms of exercise can be beneficial for improving your bone integrity, overall health, and energy level:



WALKING



**WEIGHT
RESISTANCE
EXERCISES**



YOGA



STRETCHING



TAI CHI



MEDITATION



CYCLING



**ELLIPTICAL
MACHINE**



JOGGING



SWIMMING

Being active can help you:

- Manage your weight
- Maintain muscle and bone strength
- Help with potential side effects of treatment
- Reduce anxiety and fatigue
- Improve self-esteem
- Increase feelings of optimism
- Improve heart health
- Boost muscle strength and endurance

In this video, Rob explains how his advanced prostate cancer diagnosis impacted his decision to lead an active and healthy lifestyle.

MAINTAINING HEALTH AND WELLNESS

Differences in diet and lifestyle may account for the variability of prostate cancer rates in different countries. Good nutrition may help reduce the risk of developing prostate cancer, slow progression of the disease and prevent aggressive disease. There are many resources from the [Prostate Cancer Foundation](#) about maintaining a healthy diet for good prostate health and guidelines for a healthy diet while in treatment for prostate cancer.



Many experts believe choices about our diet account for the vast majority of prostate cancer cases. It's important to evaluate diet choices when it comes to risk of prostate cancer. Scientists have slowly uncovered a list of cancer super foods and supplements to optimize in your diet while also discovering foods and supplements that could actually contribute to cancer risk.

The foods you eat help you keep up your energy levels. A healthy diet includes:

- Primarily plant-based foods
- Plenty of fruits and vegetables
- High in fiber
- Low in fat
- Limited in the amount of simple sugars

Talk to your doctor about the type of diet and foods that may be right for you.

RELATIONSHIPS

Advanced prostate cancer is your disease, but it also affects everyone who loves and cares for you. Your loved ones experience prostate cancer in a very real way.

Your loved ones' challenges may not show up on a lab chart or test result, but they are often equally important. Your diagnosis can leave them feeling helpless and confused. They, too, experience the treatments, the doctor visits, interrupted sleep, sadness, fear and grief.

“Would I live and who would I be? What would happen to us? She shared my loneliness, isolation and fear – often silently.”

- ALAN W.

While some relationships remain unchanged, you and your loved ones may have to work to find the “new normal.” This means deciding what information you want to share and with whom, and how to best approach these conversations.

- **Take time to reflect:** Your family, friends and colleagues care about you and will be open to supporting you on this journey, but you may wish to be upfront with them about what you are comfortable sharing.
- **Have a confidante:** You may benefit from having people around whom you can trust with thoughts and concerns. Who is that person for you?
- **Ask for help:** Asking for help may be difficult. But family and friends can listen, prepare a meal, run errands or drive you to an appointment – whatever you might need.
- **Seek support:** A lot of men may have similar experiences with what you are going through. Openly or anonymously, you may use an online forum or in-person support group to discuss your thoughts through this process.
- **Be understanding:** Your family and friends may be worried and tired, too. Put yourself in their shoes and consider seeking support together. It may help everyone cope during this time.

Want to talk to others who are going or have gone through what you're experiencing? The [Us TOO Prostate Cancer toll-free helpline](#) or the [PCRI toll-free helpline](#) are great places to start that conversation.

EXPLORING SEX AND INTIMACY

Maintaining intimacy when you have [advanced prostate cancer](#) can be challenging and discussing these issues with a partner or a physician can be uncomfortable, but it's best to get it out in the open. Keeping your fears to yourself can quickly lead to a sense of anger, loneliness or depression.

[Advanced prostate cancer](#) and its [treatments](#) may contribute to difficulties in sexual satisfaction. You may experience lower levels of interest, trouble or inability to achieve or sustain erections, body changes, fatigue and incontinence. Rethink intimacy during this time – establish a connection by holding one another, dancing, making romantic gestures, or anything that feels emotionally, physically and spiritually rewarding.

- **It's not just about you:** Dealing with a cancer diagnosis, deciding on or undergoing treatment and trying your best to carry on as normal can be challenging for you and your partner. It may be better to work through this challenge together. You don't have to do it alone.
- **Talk to your health care team:** As uncomfortable as talking about intimacy may be, your physician, social worker, nurse practitioner or another member of your health care team may be able to provide helpful guidance, support group suggestions or educational materials.
- **Brainstorm solutions:** Intimacy may include giving your sexual partner permission to explore alternate ways to make you feel good. Talking to your partner about ways to enhance your sex life may help you find a new path to sexual satisfaction that is different from before, but satisfying for you both. Open dialogue and creativity are key.
- **Be open:** Your sexual life together may have an impact on your whole relationship. Being proactive and open to new ideas, whether advice from a friend, health care professional, couples counselor or your partner, may help you as you

deal with these issues. Being open can lead to new solutions.

For more information and tips on intimacy and your condition, please check out informative articles from [AARP](#) and the [Prostate Cancer Foundation \(PCF\)](#).



LET'S TALK ABOUT SEX

Dr. Sharon Bober presentation at a PHEN meeting, July 2008, at Dana-Farber Cancer Institute. Dr. Bober is a psychologist with the Perini Family Survivor's Center at Dana-Farber and an instructor in psychiatry at Harvard Medical School.

OWNING YOUR STORY

Treating [advanced prostate cancer](#) means you'll be meeting with your health care team on a regular and ongoing basis –

and frequently talking to your doctors. Get to know your doctors and let them get to know you by sharing details of your life and the things that matter to you. Instead of just listing symptoms, share stories from your daily life that will give your health care team a better idea of who you are and how you're feeling.

Each time you head into the doctor's office, know the questions you want to ask. By asking questions, you'll be better informed about your journey and what comes next. Questions you might want to ask your doctors include:

MOVING BEYOND TREATMENT FOR ADVANCED DISEASE

Cancer survivorship starts at the time of disease diagnosis and continues throughout the patient's life. Survivorship is unique for each survivor. It may be 'no signs of disease' for some or living through and beyond cancer for others. Regardless of how you define it, it's important for you to consider how to transition and adjust to what being a cancer survivor means to you.

SURVIVING CANCER: WHAT TO EXPECT

At the end of active treatment, you may have mixed emotions, including relief that your treatment is over, as well as anxiety about the future. After treatment, the "safety net" of regular, frequent contact with the health care team ends. You may miss this source of support, especially because anxieties may surface at this time. Others may have physical challenges, psychological anxiety and sexual problems. Many survivors feel guilt, having lost friends or loved ones to the disease. Some survivors are uncertain about their future, while others experience discrimination at work or find that their social network feels inadequate. Find out more about coping with these concerns. Learn more about the next steps to take in survivorship.

FEAR OF RECURRENCE

Fear of recurrence (cancer that comes back after treatment) is common among most cancer survivors. It may lead a person to worry about common physical problems, such as a headaches, coughs and joint stiffness. It is hard to know what is "normal" and what needs to be reported to the doctor. Discussing the actual risk of recurrence with your doctor and the symptoms to report can often lower your anxiety. Maintaining a regular schedule of follow-up visits can also provide a sense of control. Although many cancer survivors describe feeling scared and nervous about routine follow-up visits and tests, these feelings may ease with time.

Learn more about post-treatment resources, workshops and support groups on [CancerCare.org](https://www.cancer.org)



CHANGING RELATIONSHIPS

When active treatment is over, you may need different types of support than you had before. Some friends may become

When active treatment is over, you may need different types of support than you had before. Some friends may become closer, while others distance themselves. Families can become overprotective or may have exhausted their ability to be supportive. Relationship problems that may have been ignored before cancer can surface. The entire family is changed by the cancer experience in ways they may not be aware of. Recognizing and working through these changes are necessary to help you get the support you need, and some people find that counseling helps. Open and ongoing communication helps with adapting to life and shifting relationships after cancer. Learn more about relationships and cancer through resources offered on [Cancer.net](https://www.cancer.net).

GETTING BACK TO “NORMAL”

Returning to a regular work schedule is a sign of getting back to a normal routine and lifestyle. You may have taken time off for treatment and then returned to work afterwards, or perhaps you worked throughout treatment. You may not be able to return to work because of the effects of the cancer or its treatment.



Although many survivors can be as productive as they were before treatment, some find they are treated differently or unfairly. To learn more about dealing with workplace issues, please visit the [National Coalition for Cancer Survivorship \(NCCS\)](https://www.nccs.org). During and after treatment, it may be helpful to anticipate questions from co-workers, and decide how to answer these questions in advance. Co-workers may want to help, but not know how. It may be up to you to start the conversation and set the limits. When and how you choose to discuss your situation is a personal decision. Find out more about sharing your story.

To talk to others who are going or have gone through what you're experiencing, the [Us TOO Prostate Cancer toll-free helpline](https://www.us TOO Prostate Cancer toll-free helpline) is a great place to start.

PLANNING AHEAD

No matter how far off it may be, it is difficult to think about an end-of-life plan. Talking about it with your family can be even harder. But your loved ones are here to help you. Share with them how you feel, what is important to you and what

you want out of your care.

Having a plan in place can help you cope and help ease the process for you and your loved ones. In the long run, it can ease stress, anxiety and emotional distress.

Starting the discussion with your doctor about your care needs can lead you to local palliative and hospice care resources. An interdisciplinary hospice team (e.g., your doctor, hospice physician, nurse, home health aide, social worker and others) will have helpful resources to support you and your loved ones, including:

HOSPICE TEAM SUPPORT SERVICES

- **MANAGING PAIN AND SYMPTOMS**
- **ASSISTING WITH EMOTIONAL, PSYCHOSOCIAL AND SPIRITUAL NEEDS**
- **PROVIDING NEEDED DRUGS, MEDICAL SUPPLIES AND EQUIPMENT**
- **COACHING THE FAMILY ON HOW TO CARE FOR THE PATIENT**
- **DELIVERING SPECIAL SERVICES, LIKE SPEECH AND PHYSICAL THERAPY, WHEN NEEDED**
- **MAKING SHORT-TERM IN-PATIENT CARE AVAILABLE WHEN PAIN OR SYMPTOMS BECOME TOO DIFFICULT TO MANAGE AT HOME, OR THE CAREGIVER NEEDS A BREAK**
- **PROVIDING BEREAVEMENT CARE AND COUNSELING TO SURVIVING FAMILY AND FRIENDS**

There are helpful resources such as the [Cancer Support Community](#), which provides some directive advice on planning ahead with your loved one.

CAREGIVER Q+A: DO SUPPORT GROUPS WORK?



Sharon, from Massachusetts, tells us about attending support groups with her husband.

- **WHEN DID YOUR PARTNER FIND OUT HE HAD PROSTATE CANCER?**
My husband, Chris, was diagnosed in 2014 with prostate cancer. He was 58 years old.
- **WHAT WAS YOUR INTRODUCTION TO CAREGIVING LIKE?**
I felt completely overwhelmed with all the information. I desperately needed help and support.
- **WHERE DID YOU GO FOR SUPPORT?**
Through a friend at church, I found out about Prostate Health Education Network, also known as PHEN. My husband and I started going to PHEN meetings together.
- **HOW DO THE MEETINGS WORK?**
The support-group meetings were 2-part. In the first hour, all the men with prostate cancer and their caregivers would hear information together. Then, 2 groups would break out, one for the men and one for the caregivers, so each group could chat.
- **DID YOU SEE A POSITIVE DIFFERENCE AFTER MEETINGS?**
Oh, yes. A tremendous weight was lifted off my husband, Chris's, shoulders immediately after talking with the other men. It was also easier, after the meetings, for him to open up to me about what was really going on with him, how he was feeling.
- **WHAT DID YOU GET FROM THE MEETINGS?**
Connecting with other caregivers was so helpful. I could share my frustrations with them, and they understood how so many people, who weren't doctors but had somehow been impacted by prostate cancer, were offering us all sorts of treatment options, even "homemade" remedies. That was frustrating, and I could talk about it—the other caregivers got it.
- **DO YOU STILL GO TO GROUPS?**
I actually volunteer now, helping to organize PHEN events. I was just so happy with how they helped us. And my husband, Chris, still goes to the support groups...more often than I do! I think he just really enjoys being with the men.

- **HOW CAN I FIND A LOCAL PHEN MEETING?**

It's easy! Just go online to ProstateHealthEd.org, and click on the city closest to you in the box at the top right to find a local group.

FIND A SUPPORT GROUP NOW:

- **VISIT:** ProstateHealthEd.org or UsTOO.org
- **CALL:** PHEN at (617) 481-4020 or [UsTOO](http://UsTOO.org) at (800) 808-7866

CAREGIVER CHECKLIST: 5 THINGS EVERY CAREGIVER NEEDS TO DO TODAY

KEEP THIS BE-GOOD-TO-YOU CHECKLIST HANDY TO HELP PREVENT CAREGIVER BURNOUT. ¹

"Caregiving can swallow you whole," says Sharon, from Massachusetts, whose husband Chris was diagnosed with prostate cancer at 58. "You hear cancer, and a huge fear overwhelms you. I knew Chris had to face this, and I could see the flood of worry racing through his mind. I wanted to support and care for him, and not let on how afraid I was," she says about taking on her new caregiver role.

It can be terrifying seeing the man you love get struck down by illness. But in our jump to the rescue, we can end up piling too much onto our shoulders, leading to burnout, exhaustion, even depression. ²

Everything became cancer related. Finally, I learned that to be my best for him, I had to take care of myself.

SHARON
RANDOLPH, MASSACHUSETTS

Sharon began planning small weekly treats: walking with friends, indulging in healthy desserts, playing upbeat music, praying or checking in with her support group. "I started feeling heaps better." Stay healthy with the take-care-of-you checklist below.

5 THINGS SHARON & EXPERTS SUGGEST CHECKING IN ON DAILY. START

NOW!



YOUR CAREGIVER CHECKLIST

**WHETHER TAPED TO THE BACK OF A DOOR, OR SLIPPED
INTO YOUR WALLET, KEEP THIS HANDY!**

HAVE YOU ASKED FOR WHAT YOU NEED? ³

Yes, it's hard to ask for help. But friends who offer want to support you. Fresh loads of laundry? A healthy supper? A grocery run? Jot down 3 things you could use today—and tell someone who asks. Need help of thinking of ways others can help you? First, you may want to map out all of your caregiving tasks in this Caregiving Planning Guide – then you can determine what others can help with, and assign them one of the tasks you outlined in your guide. ([CLICK FOR ARTICLE HERE](#)) ⁴

HAVE YOU CHECKED YOUR STRESS LEVELS?

Enemy #1: Stress. Caregivers report higher stress levels than others, which can prompt illness. ⁵

- Pick 2-3 stress-busters, and dedicate 30 minutes daily.
- Watch a comedy, or do yoga, Tai Chi, meditation or breathing exercises. ⁶
- Or try Cleveland Clinic's Stress Free Now app. ([DOWNLOAD APP HERE](#))

HAVE YOU PUT SLEEP STRATEGIES IN PLACE?

It's no shocker: You need more sleep. One study found half of caregivers got inadequate sleep, causing daytime fatigue. ⁷ Try these proven tricks:

Skip big meals before bed, and keep your bedroom cool and dark—and TV and electronic-device screens out of it. ⁸ Also try these 5 Secret Sleep Tools. ([CLICK TO SEE INFOGRAPHIC](#))

HAVE YOU GOTTEN OUTSIDE YET?

It's 4:00 p.m. Been outdoors? Even if it's for a 10-minute walk around the block, you'll be surprised at the energy boost and calm a short stroll can bring. ⁹ Set this one as your goal: get outdoors daily. If you just can't swing it, look at nature photos, which can also be stress-lowering, finds research. ¹⁰

DID YOU TALK IT OUT TODAY?

Be good to yourself: schedule a 20-minute phone conversation weekly with friends you can open up to. Research shows that laughter is an especially potent stress buster. ¹¹ Support groups also provide relief, and connect you with other caregivers. Sharon and Chris found a healthy outlet at Prostate Health Education Network (PHEN).

NEED SUPPORT?

- **EMAIL PHEN:** RapCancer@ProstateHealthEd.org
- **CALL:** (617) 481-4020

REFERENCES

- [1] Family Caregiver Alliance. Caregiver Health. <https://www.caregiver.org/caregiver-health>. Accessed April 2016.
- [2] Family Caregiver Alliance. Caregiver Health. <https://www.caregiver.org/caregiver-health>. Accessed April 2016.
- [3] Women's Health. Caregiver Stress. <http://www.womenshealth.gov/publications/our-publications/fact-sheet/car...> Accessed April 2016.
- [4] AARP. Caregiving Resource Center. <http://www.aarp.org/home-family/caregiving/caregiving-tools/>. Accessed April 2016.
- [5] Women's Health. Fact Sheet. <http://www.womenshealth.gov/publications/our-publications/fact-sheet/car...> Accessed April 2016.
- [6] Women's Health. Fact Sheet. <http://www.womenshealth.gov/publications/our-publications/fact-sheet/car...> Accessed April 2016.
- [7] Carney S, Koettters T, Cho M, et al. Differences in sleep disturbance parameters between oncology outpatients and their family caregivers. *J Clin Oncol* 2011; 29(8):1001-1006
- [8] National Sleep Foundation. A Great Night's Sleep Can Depend on the Visual Conditions in Your Bedroom Environment. <https://sleepfoundation.org/bedroom/see.php>. Accessed April 2016.
- [9] Anxiety and Depression Association of America. Exercise for Stress and Anxiety. <http://www.adaa.org/living-with-anxiety/managing-anxiety/exercise-stress...> Accessed April 2016.
- [10] The Dirt: Uniting the Built Natural Environments. Research Shows Nature Helps With Stress. <https://dirt.asla.org/2011/09/08/research-shows-nature-helps-with-stress/>. Accessed April 2016.
- [11] Mayo Clinic. Healthy Lifestyle: Stress Management. <http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/s...> Accessed April 2016.

WHO'S WHO ON YOUR HEALTH TEAM

AND WHY THERE ARE SO MANY MOVING PARTS!

When your diagnosis is advanced prostate cancer, you'll soon have a powerful force built around you in the form of a healthcare team. You may already have a variety of medical pros and specialists working together to bolster care for you and your family. Good news: From oncologists to nutritionists, you'll have a whole army of experts joining you in this fight. Your crucial role? To speak up whenever you have questions, and persist in your quest for answers.



HERE'S A LOOK AT THE MEDICAL PROS WHO MAY JOIN YOUR HEALTH TEAM:

UROLOGIST

A doctor whose specialty is treating disease of the urinary and sex organs.

UROLOGIC ONCOLOGIST

A doctor who diagnoses and treats cancers of the genital and urinary organs.

RADIATION ONCOLOGIST

A medical specialist trained to use radiation to treat cancer.

MEDICAL ONCOLOGIST

A medical doctor who diagnoses and treats cancer with chemotherapy and other drugs.

ONCOLOGY AND UROLOGY NURSES

Nurses are medical pros who work to observe and report what the patient is experiencing, feeling, and how

they are doing to keep healthcare providers informed on the status of the patient.

PHYSICAL THERAPIST

A trained exercise pro who may help you ease side effects, lower stress and combat depression.

NUTRITIONIST

A dietary pro who advises on healthy foods to eat for boosted strength, immunity and energy.

ONCOLOGY SOCIAL WORKER

A trained therapist who offers coping tools, talk therapy and emotional support for you and your family.

SPOTLIGHT: ONCOLOGY NURSE

AN MVP OF YOUR HEALTHCARE TEAM

"Bill was sheepish at first," says Joanne, who was his oncology nurse. Bill had been healthy as an ox. The 55-year-old father of 3 served honorably in the military. He was a pillar of the community.

"He'd proudly rattle on about his experience in the military and knew every facet of his kids' lives," says Joanne, "but facing an advanced prostate cancer diagnosis, Bill and his wife were lost.

" First things first, Joanne connected with Bill the person, not just Bill the patient she'd care for. Once they had a rapport going, Joanne got real, saying:

Bill, you have to empower yourself to work closely with your team to navigate this disease...not let it control you.

JOANNE ONCOLOGY NURSE

Joanne saw fear melt away, the message sink in. "After two weeks, Bill came back a fighter. He was ready to tackle his new job, of fighting advanced prostate cancer in partnership with his healthcare team," she says.

BEYOND BEING YOUR TEAM'S EYES AND EARS, HERE ARE MORE KEY ROLES ONCOLOGY NURSES (ONS) PLAY:

THE GLUE: You'll have up to 9 (or more!) pros on your healthcare team. ONs play a vital role in coordinating all the moving people and parts of your treatment.

TRUTH DETECTOR: ONs have the unique vantage point of being on the "front lines" of patient treatment, as they get to spend a lot of time with the patients and get to know them well. Treatments wiping you out? Side effects taking a toll? ONs often know, even if you don't say. "Men tend to sweep symptoms under the rug. We know. And get to the truth anyway."

MASTER EXPLAINER: Your ON knows your full treatment plan and can walk you through, step by step.

CONSTANT COMPANION: Whomever you're visiting at the clinic, your ON is likely to pop by to see you. "Men may not be as open as women, but their anxieties, fears, frustrations...their needs are the same." Your ON is with you on this

journey, the friendly face you can count on.

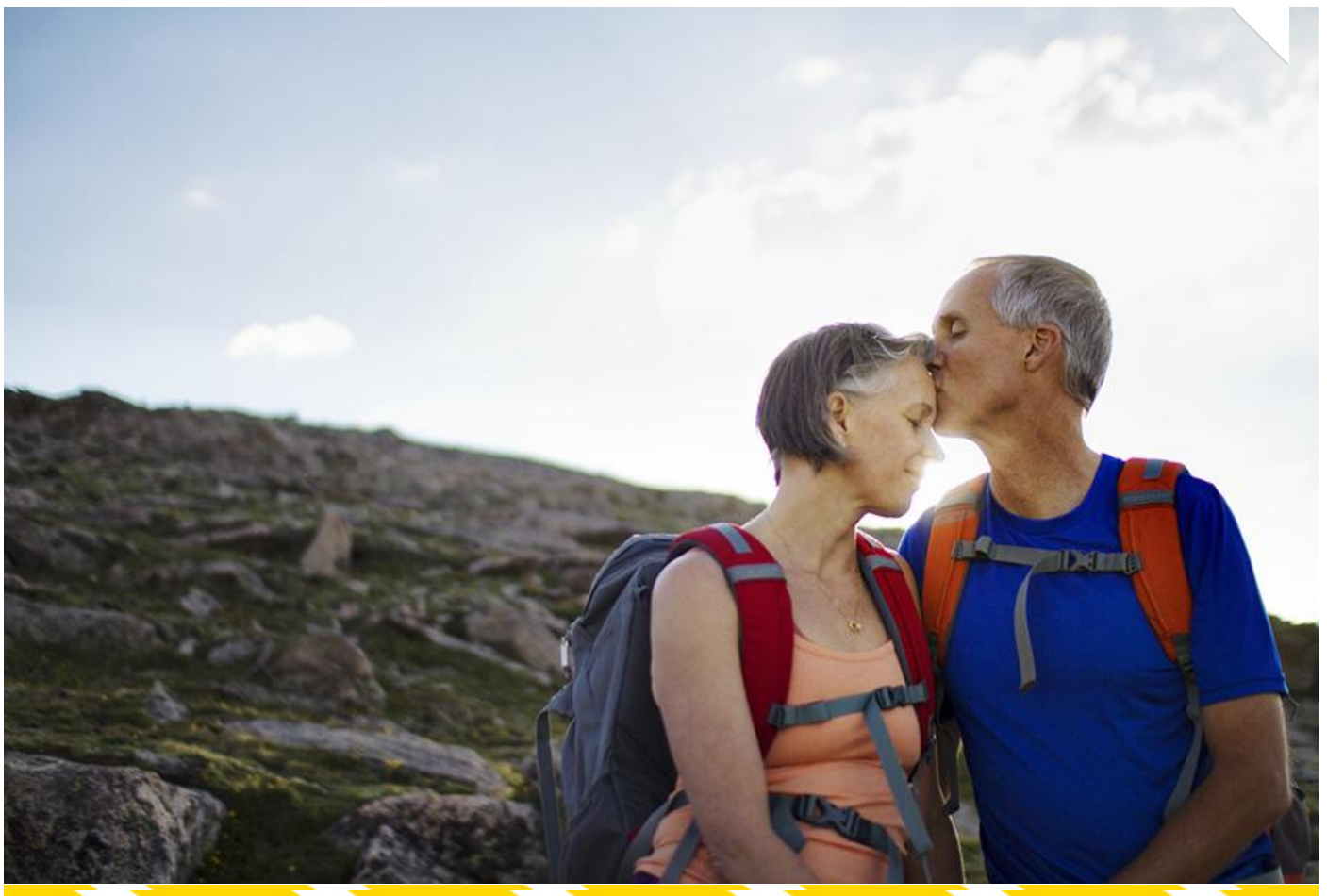
As told by Joanne M. Vanak, RN, MSN. Once an oncology nurse, Joanne is now Senior Director, Scientific Advocacy at Janssen Biotech, Inc.

THE ROAD TOGETHER

As the loved one of a man with [advanced prostate cancer](#), you may take on many roles in the course of your loved one's prostate cancer journey. Family members and close friends often face the stresses associated with caring for a loved one, as well as trying to navigate their own fears and concerns.

FOSTER OPEN COMMUNICATION

Health discussions between you and your loved one can be a minefield, as complicated as fights about finances or asking for directions. For many men used to being strong and feeling in charge, facing medical fears can be overwhelming, especially when it comes to advanced prostate cancer. Be prepared to do a lot of the heavy lifting, such as scheduling the appointments, supporting your loved one during follow-up with physicians' offices and implementing physicians' advice at home.



There are many resources for those who are diagnosed, and you can work with your loved one and their health care team to navigate treatment options and support him on his journey. One of the keys is creating an environment built on open and honest conversation. It can be tough, but there are many things you can do to avoid a situation in which worrisome symptoms or situations go unacknowledged.

CAREGIVER TIPS: NAVIGATING TOGETHER THROUGH ADVANCED PROSTATE

CANCER

- **Speak Up When Something Seems Off:** As a caregiver, you may be the first to notice when your loved one is not feeling well, even if he is not willing to admit it, or might not even see it – particularly if he is experiencing side effects such as fatigue or dizziness. Pay attention to what is going on with your loved one's health and do not be afraid to gently ask questions and, if needed, be insistent. Concern for his well-being is not negativity or criticism.
- **Do Not Get Righteous:** Jumping on a soapbox seldom works. Instead of attempting to single-handedly “fix” and “save” your loved one, work together on a health plan that works for you both.
- **Quietly Flip the Script:** If you want to change the way your loved one eats, work with him to make grocery lists that include fresh, healthy foods. Explore recipes for lower-fat, lower-sodium versions of the meals he loves. Try new restaurants that serve healthier options – and don't hesitate to ask restaurant staff about alternative ways to prepare menu items to make them healthier. Keep water on hand as an alternative to sugar-laden drinks. If he will not go to the doctor, you could ask him to go with you to your family doctor appointment.
- **Lead by Example:** When finding the energy to care for loved ones, you may find that it takes a toll on your ability to nurture your own health and well-being. It is important to make time to keep yourself healthy and strong as well. Show him how to lead a healthy lifestyle by leading one yourself.

You're there to support your loved one when he needs it. When the going gets rough, and it may, you have to keep going because you love him.

Your relationship with your loved one will be stronger if you work as a team and open up to each other.

Patti, Rob's wife, explains how she supports her husband throughout his experience with advanced prostate cancer.

HELP FACILITATE PRODUCTIVE VISITS

It's helpful for your loved one to get as much information as possible from his health care team during his appointments. The following questions can be helpful in guiding conversations with his health care team.

UNDERSTANDING PROSTATE CANCER

- What type of prostate cancer does he have?
- What is prostate-specific antigen (PSA) and what does it mean?
- What is a Gleason score and what does it mean?
- What is androgen, and what role does it play in prostate cancer?
- What are the main sources of androgen in the body?
- Can you help us find disease and therapy information on the Internet from a reliable source?

WHAT YOU CAN EXPECT

- Can he still work while he is being treated?
- Where should we go for help with our insurance questions?
- What if we have trouble paying for treatment?
- Who is our primary health care contact?
- Who will be on the health care team and how do we contact them?

TREATMENT OPTIONS

- How long will treatment last?
- What treatment options are available for him? What are the risks and benefits of each?

- Have you treated many patients with cancer like his?
- Which treatment do you recommend? How does the treatment work?
- What are the chances that his treatment will work?
- How will you know the treatment is working?
- What are his options if the treatment doesn't work?
- Should we get a second opinion? Is there someone else we should speak with?

IMPACT OF TREATMENT(S)

- How will the treatment affect his daily life?
- How will the treatment make him feel when he wakes up in the morning and then during the day as he goes about his usual activities?
- Will he still be able to be active and do physical activities?



ENCOURAGE HEALTH AND WELLNESS

Work with your loved one's health care team to ensure all appropriate measures are taken to maintain his overall physical and emotional health while in treatment or palliative care.

Adequate nutrition and physical activity can play an important role in helping patients to continue working or volunteering, as well as maintaining recreational and social activities:

- **Give Reminders:** Reminding your family member or friend to eat and stay hydrated may help him regain strength and stamina.
- **Exercise Together:** Participating in your friend's or loved one's exercise regimen may help motivate him. Consider activities you can do with family or friends that are fun and healthy – these can also be great ways to build memories.
- **Take Note:** A change in your loved one's symptoms or energy level could be a reason to contact his health care team about his nutrition and exercise regimen.
- **Take Care:** Taking care of your own mood and mental health can play an essential role in making sure you can be there to support your family member or friend. There are many support groups and medical societies that may be helpful to you.

Sexual intimacy is another difficult topic to broach, but there are steps you can take to support him there as well:

- **Be Engaged:** Participating in conversations about sex and intimacy with your partner and his health care team, and considering individual counseling may help you deal with issues related to sex and intimacy.
- **Show Compassion:** Whether or not sex is a critical part of your relationship, research has shown a man's sense of

masculinity is often tied to his sexual capability.

- **Express Yourself:** While your primary concern is likely to be for your partner, you have a right to all of your thoughts and feelings. Expressing these concerns may actually lead you to take steps that will help both of you achieve intimacy.

PROVIDE EMOTIONAL SUPPORT

Dealing with emotions is an essential part of this difficult experience, and it's not one size fits all. By nature, people may have different styles of communication. However, many others have been through this, and there are resources such as:

- [American Cancer Society's Cancer Survivors Network](#), which has ways for caregivers to connect with other caregivers.
- [CancerCare's Educational Workshops](#), which provide up-to-date information about cancer-related issues and offer practical tips on how to cope with a loved one's cancer.
- [National Cancer Institute's Caring for the Caregiver Booklet](#), which provides ways for caregivers to take care of themselves while caring for someone with cancer.

Some men feel that showing their emotions is a sign of weakness, where women can be more open to sharing feelings. These differences can cause anger, anxiety and even result in physical symptoms.

Emotions can also make decision making more difficult. Your loved one needs to know that these feelings are normal and that he is not alone. Listening is now more important than ever. He may not like to talk about his disease, treatments or fears. Depending on your loved one, it might be best if you don't push him to talk. Instead, let him know that you will be there when he needs you – when he is ready.



You might speak with your loved one about seeing a psychologist or psychiatrist for one-on-one sessions. Joining a prostate cancer support group can be another option for those seeking emotional support. Some men may feel more comfortable talking with men who are going through a similar experience. There are in-person support groups

and others that can be found online.

Remember that your loved one may sometimes want to talk to his doctor alone so he can address his questions and fears without upsetting you, or for his own reasons. You are still an important part of his prostate cancer journey. You can also request to speak with members of his health care team; they may not be able to reveal confidential health information, but you can share your observations or concerns.

SUPPORTING CAREGIVERS

Although prostate cancer strikes men only, it can have a profound influence on their family and caregivers. Those closest to you often face the stresses associated with caring for a loved one, all while trying to navigate their own fears and concerns.

Although it is natural to feel many emotions including anxiety, fear and frustration, it is important to take charge of managing [advanced prostate cancer](#) and to recognize that knowledge is power. It can reduce some of the anxiety and confusion that comes with a diagnosis of advanced prostate cancer and is a prerequisite for making the best treatment choices given the unique circumstances and conditions that are specific to each diagnosis.

It is a tough fight, and you may feel alone or just overwhelmed. Do not be afraid to ask for help – or accept it – from friends, family and community members. If you are feeling alone or isolated, let your family and friends know that just a phone call or text message to check in on you means a lot – just so you know you have support when you need it.



FIND SUPPORT

While trying to cope with the day-to-day physical, emotional and financial challenges that accompany living with advanced prostate cancer, it can be beneficial for you and your loved one to talk with others who are having or have had the same experiences. Collaborating with your peers can provide emotional support as well as valuable treatment information, advice and tips from others who have “been there and done that.” There are many support groups for you, your loved one and other family members. Encourage your loved one to attend a support group meeting, join an online support community or call [Us TOO's toll-free helpline](#).

EXPLORE SUPPORT PROGRAMS AND RESOURCES

- [Circles of Love](#): An education and support program for companions and families of prostate cancer patients
- [My Bridge for Life](#): Provides digital health tools designed to empower patients and caregivers to actively manage their health and wellness
- [“Outer-course vs. Inter-course”](#): An article by Dr. Joan Baldwin Peters, on sexual intimacy suggestions and tips
- [Us TOO's Toll-free Helpline](#): Connects callers to a prostate cancer survivor or caregiver who understands

