



International Prostate
Cancer Foundation



PROSTATE CANCER Caregiver Guide

*A comprehensive resource on caregiving
for a prostate a cancer diagnosis.*

fightingprostatecancer.org

INTRODUCTION

About this guide

There are no two ways about it: having a cancer diagnosis in your family is hard and life changing. Despite increasing optimism about treatment, today's cancer landscape can be challenging as patients and caregivers have access to an unprecedented amount of information.

There are literally millions of cancer-related webpages, blogs, and videos available at your fingertips. A cancer diagnosis can be disorienting, and for many, the overwhelming volume of information available can be more of a burden than an aid. And from the caregiver's perspective, understanding how to lend support to a man on this journey can be difficult.

Caregivers may take on many roles during a man's prostate cancer journey. When a loved one is diagnosed with prostate cancer, those around him may find that they quickly have to become an information specialist, a financial advisor, a medical translator, and a source of emotional support.

The Prostate Cancer Caregiver Guide is not intended to be followed like a book that you read from beginning to end. Rather, it can be referenced, as needed, for each topic that is **relevant to your care experience**. Caregivers can be friends, family, or loved ones. Anyone can be a caregiver for a man with prostate cancer. This guide focuses all the information available about caregiving for prostate cancer into one consolidated resource. It is for any person(s) who have a newly diagnosed loved one, who is in treatment, or is concerned about a rising PSA.

Who should read this guide?

All caregivers, family, and friends of a loved one diagnosed with prostate cancer could benefit from reading this guide. Beyond that, it's for anyone who wants to cut through the information overload and confusion and get directly to need-to-know information for prostate cancer patient care.

To learn more about prostate cancer and for the most update information please visit fightingprostatecancer.org. It may also be helpful to download the Prostate Cancer Guide Vol. 1 from the resources center of the website. It provides more in-depth information about prostate cancer, prostate cancer research and prostate cancer treatments.

Making sense of medical terms

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you and it may be a lot to learn. Reference the glossary in the back of Prostate Cancer Guide Vol 1. for the definitions of terms.

Don't be discouraged. Review the information. Don't be intimidated to ask your treatment team to explain a word or phrase that you do not understand.

About IPCF

Founded in 2008, The International Prostate Cancer Foundation is a not-for-profit charitable organization with a voluntary faculty of international expert physicians and survivors who have joined in the fight against prostate cancer. Founded to fill a void in men's health advocacy, to raise awareness and to support scientific advances in prostate cancer. Our mission is to cure those afflicted with the disease and to help prevent it in those who are predisposed to it.

Conceived by cancer survivors, our mission is clear, and our approach is unique. Our foundation is led by Dr. Vipul Patel, a practicing urologist with a worldwide patient base. This, combined with our expert volunteer board, gives us a unique perspective of the disease on both a clinical and non-clinical level.

The spirit of our foundation is formed from the inspiration of our doctors, patients, and healthcare advocates. Our mission is to serve, educate, and innovate to help men understand the risks and what to do if they are diagnosed with prostate cancer.

Subjects depicted are models and are used for illustrative purposes only. Prostate cancer standards of practice change regularly. For the most up-to-date information, please visit fightingprostatecancer.org and consult a healthcare professional.

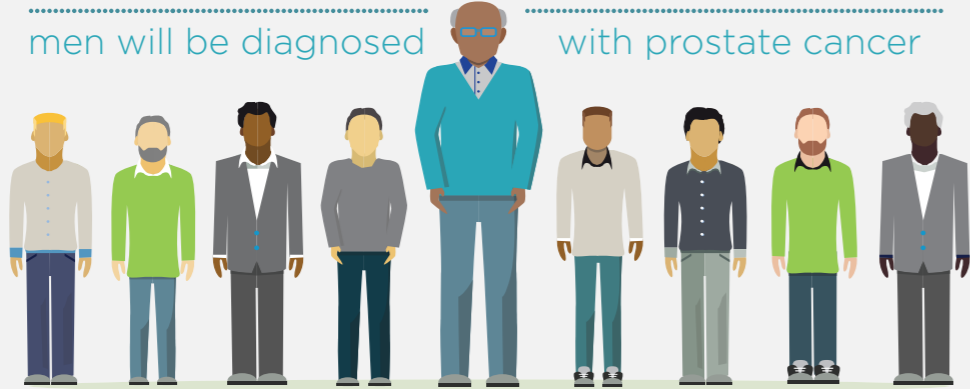
This guide was produced in 2020-2022 by the International Prostate Cancer Foundation (IPCF). Founded in 2008, The International Prostate Cancer Foundation is a not-for-profit charitable organization.

This guide is provided to the public to disseminate health-related information. The included information is not intended to be used for diagnosing or prescribing. Please consult your physician before undertaking any form of medical treatment and/or adopting any exercise program or dietary guidelines. The information resources listed are not the property of the International Prostate Cancer Foundation. The International Prostate Cancer Foundation does not assure the accuracy or timeliness of the information and provides these references for your convenience only.

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one in nine

men will be diagnosed with prostate cancer



make a plan, get
TESTED



learn your risk
from your doctor

**AFRICAN AMERICAN MEN ARE TWICE
as likely to die from prostate cancer**

With early diagnosis and treatment, survival rates are over **90%**

Having a father/brother diagnosed
more than doubles a man's risk

a man dies
**EVERY
19mins**
of prostate cancer



a man is diagnosed
**EVERY
2.4 mins**
with prostate cancer



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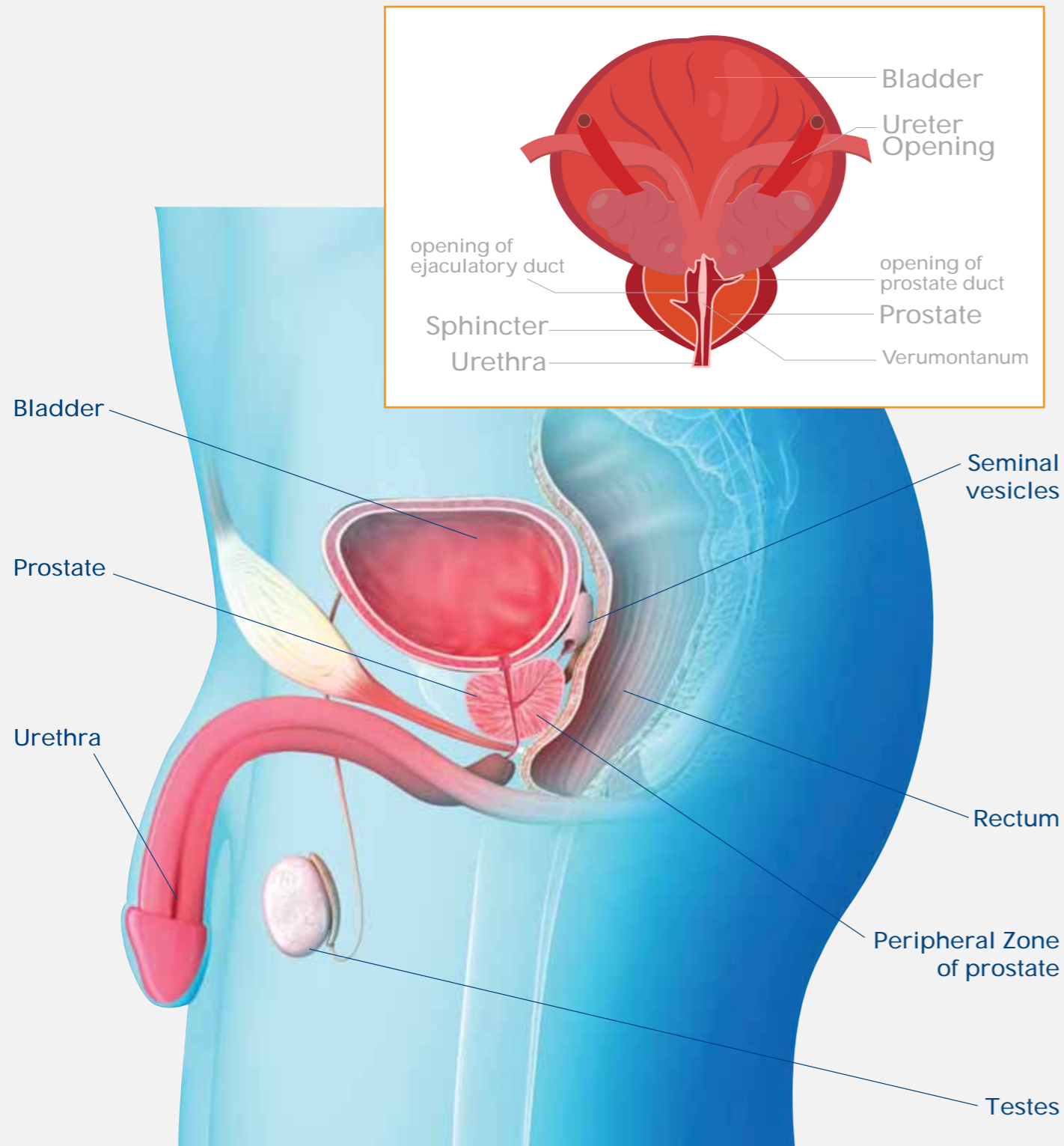
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ANATOMY OF THE PROSTATE

The prostate gland looks like a chestnut, is located just below the urinary bladder and is run through by the urethra.



1. WHAT YOU NEED TO KNOW ABOUT YOUR LOVED ONE'S PROSTATE CANCER

About Prostate Cancer — General Information

According to the *National Cancer Institute*, prostate cancer is the second most common type of cancer among men in the United States. Men with certain risk factors are more likely than others to develop the disease.

Published data suggests that one of the most important factors in treating prostate cancer is *early diagnosis and accurate treatment* by experienced doctors. Before a treatment plan is determined, however, it is important to understand the disease and to research all the options available.

Cancer is a condition in which a normal cell becomes abnormal and starts to grow uncontrollably without having the signals or “brakes” that stop typical cell growth.

Prostate cancer starts in the prostate gland, a small gland located below the bladder, that is responsible for secreting one of the components of semen. Prostate cancer develops when abnormal cells in the prostate gland start to grow more rapidly than normal cells, and in an uncontrolled way. Most prostate cancers grow more slowly than other types of cancer, and even the more aggressive prostate cancers tend to grow more slowly than other types of cancer. Compared with other cancers, prostate cancer has one of the highest five-year survival rates.

In many cases, prostate cancer is relatively slow growing, which means that it takes several years to become large enough to be detectable, and even longer to spread outside the prostate, or metastasize. However, in some cases the growth is more aggressive and may need more urgent treatment.

Many men live with prostate cancer for many years without symptoms and without it spreading. Early (or localized) prostate cancer means cancer cells have grown but, as far as it is possible to tell, have not spread beyond the prostate.

The Anatomy of the Prostate

The prostate begins to form while a baby is inside his mother's womb. After birth, the prostate keeps growing and reaches nearly full-size during puberty. At this point, it is about the size of a walnut. Testosterone causes the prostate to grow slowly in most men. However, the prostate may grow to a large size in some men and cause problems in passing urine.

The prostate sits under the bladder and in front of the rectum. The prostate is only present in men and is important for reproduction, because it supplies the fluids needed for sperm to travel and survive (sperm is not made in the prostate; it is made in the testes). This white-colored fluid mixes with the sperm and other fluids to form semen. Semen is ejected from the body through the penis during ejaculation. The fluid from the prostate specifically protects sperm from the acid inside a woman's vagina.

The prostate is divided into several anatomic regions, or zones. Most prostate cancer starts in the peripheral zone (the back of the prostate) near the rectum. That's why examining the prostate via a gloved finger in the rectum, known as digital rectal exam (DRE), is a useful screening test.

The seminal vesicles are rabbit-eared structures that store and secrete a large portion of the ejaculate. These structures sit on top of the prostate. The neurovascular bundle is a collection of nerves and vessels that run along each side of the prostate, helping to control erectile function. They are usually a short distance away from the prostate, but sometimes they attach to the prostate itself.

The bladder is like a balloon that gets larger as it fills up, holding urine until the body is ready to void. The urethra, a narrow tube that connects to the bladder, runs through the middle of the prostate and along the length of the penis, carrying both urine and semen out of the body; it is the hose that drains the bladder.

The rectum is the lower end of your intestines that connects to the anus, and it sits right behind the prostate.

As shown in the illustration, the prostate is located below the bladder near the base of the penis. Urine from the bladder travels through the urethra, which passes through the prostate and into the penis. Above the prostate and behind the bladder are two seminal vesicles. Seminal vesicles are also glands that make a fluid that is part of semen.

Inside the prostate, 30 to 50 small sacs make and hold the white-colored fluid. The fluid travels in ducts to the urethra during ejaculation. Around the sacs and ducts is connective tissue.

The Biology Of Prostate Cancer

To properly understand diagnosis and treatment options, it's important to understand how prostate cancer grows. A normal prostate uses androgens (including testosterone and dihydrotestosterone, or DHT) during its development and everyday function. Once prostate cancer forms it feeds on androgens and uses them as fuel for growth. This is why one of the backbones of treatment for men, especially with advanced prostate cancer, is to lower a man's androgen levels with drugs collectively termed "hormone therapy."

Prostate cancer occurs when a normal prostate cell begins to grow out of control. In many cases, prostate cancer is a slow-growing cancer that does not progress outside of the prostate gland before the time of diagnosis.

Prostate cancers that are composed of very abnormal cells are much more likely to both divide and spread faster from the prostate to other regions of the body. Often, prostate cancer spreads first to tissues that are near the prostate, including the seminal vesicles and nearby lymph nodes.

Researchers have identified various biological and genetic subtypes of prostate cancer. It is possible for any given prostate cancer tumor to contain multiple subtypes of prostate cancer. Doctors and researchers are only just now beginning to use subtyping to guide treatment recommendations, thanks in part to active and ongoing research. (see understanding your diagnosis for more detailed information on the types.)

What Is Prostate Cancer?

Prostate cancer is a type of urologic cancer — a group of cancers that affect the urinary system. Prostate cancer starts within cells of the prostate gland, which is only found in men. The prostate gland surrounds the urethra and produces seminal fluid. Normally, these cells grow and divide to create new healthy cells as the body needs them. These healthy cells replace the old or damaged cells that die. It is a balanced process when it works right.

When the balance is off, a damaged or old cell does not die and isn't removed by the body's immune system. This cell then creates new, faulty cells that keep dividing uncontrollably, which may cause tissue growths called tumors.

Cancerous tumors are dangerous because the cancer cells can spread into nearby tissues, or metastasize. They can grow or break off and travel into other places in the body through the blood or lymph system, forming new tumors.

What Causes Prostate Cancer?

Medical professionals and researchers aren't completely sure what causes prostate cancer. It's likely that several different factors come into play, but researchers are still investigating which factors have the greatest impact and how they cause the cancer to develop. At a very basic level, researchers know that prostate cancer develops as a result of DNA mutations in one or more prostate cells. These DNA mutations may be inherited.

For instance, some people are born with tumor suppressor genes (RNASEL, BRCA1 and BRCA2) that don't function the way they should. This can allow cancerous cells to develop, grow and eventually form a tumor.

Caused by increased hormone levels. For instance, too many androgens (male hormones, such as testosterone) may program prostate cells to grow at an abnormally high level, and DNA mutations may occur as a result.

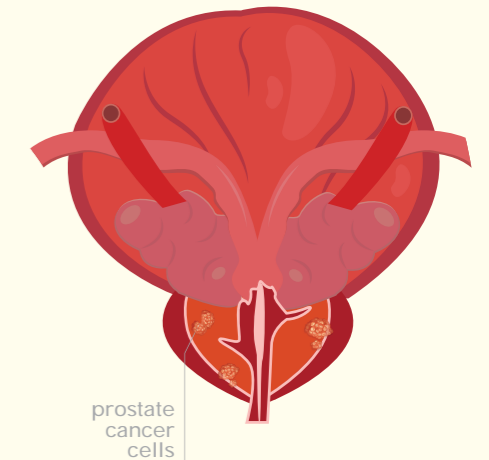
Acquired over time. Although the correlation isn't fully understood, being obese or over the age of 50 are risk factors for prostate cancer. These aren't proven causes of prostate cancer, but rather can make a person's DNA more likely to mutate over time.

Is There A Cure For Prostate Cancer?

When people think about cancer treatment success, they often think of the word "cure." Sometimes statisticians think of "cure" as a function of time: is 5 years without a cancer recurrence equal to a cure? Or is it 10 years? Unfortunately, in some men, prostate cancers can recur even 10 years after treatment. So instead of using the term "cure," doctors commonly use terms such as biochemical control (PSA levels kept at bay with medication) or freedom from developing metastatic disease (the cancer has not spread to distant organs) to help quantify the success of prostate cancer treatment.

WHAT IS PROSTATE CANCER?

Prostate cancer develops when abnormal cells in the prostate gland start to grow more rapidly than normal cells in an uncontrolled way.



WHAT ARE THE SYMPTOMS OF PROSTATE CANCER?

- ✓ weak or interrupted flow of urine
- ✓ painful ejaculation
- ✓ blood in the urine or semen
- ✓ frequent urination (especially at night)
- ✓ painful urination
- ✓ persistent pain in the back, hips or pelvis

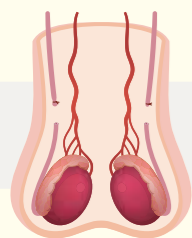
PROSTATE CANCER RISK MYTHS

The below have been disproven
as prostate cancer risks.



Sexual Activity

Medications



Vasectomy

Vitamin E



Alcohol Consumption

Risk Factors

A risk factor is anything that affects your chance of getting a disease. Different cancers have different risk factors. Some risk factors, like smoking or diet, can be changed. Others, like a person's age or family history, can't be changed.

Having one or several risk factors does not mean that you will get the disease. Many people with one or more risk factors never get cancer, while others who get cancer may have had few or no known risk factors.

Age: Age is the main risk factor for prostate cancer, and the disease is rare in men younger than 45; only 1 in 10,000 men under age 40 will be diagnosed. However, with advanced screening, men as young as 30 have been diagnosed and treated for prostate cancer. The chance of getting prostate cancer increases sharply as a man gets older. In the United States, more than 65% of all prostate cancers are diagnosed in men over the age of 65.

Family History: A man's risk is higher if his father or brother had prostate cancer. This risk is further increased if the cancer was diagnosed in family members at a younger age (less than 55 years of age) or if it affected three or more family members.

Geography: Prostate cancer is most common in North America, northwestern Europe, Australia, and the Caribbean islands. It is less common in Asia, Africa, Central America, and South America.

The reasons for this are not clear. More intensive screening in some developed countries probably accounts for at least part of this difference, but other factors such as lifestyle differences, such as diet, are likely to be important as well.

Race: It is more common in African-American men than in Caucasian men. It is less common in Asian and Native-American men.

Certain Prostate Changes: Men with cells called High-Grade Prostatic Intraepithelial Neoplasia (PIN) may be at increased risk. These prostate cells look abnormal under a microscope.

Inflammation of the Prostate: Some studies have suggested that prostatitis (the inflammation of the prostate gland) may be linked to an increased risk of prostate cancer, but other studies have found no such link. Inflammation is often

seen in samples of prostate tissue that also contain cancer. The link between the two is not yet clear and is an active area of research.

Certain Gene Changes: Several inherited gene changes seem to raise prostate cancer risk, but they probably account for only a small percentage of cases overall.

For example: Inherited mutations of the BRCA1 or BRCA2 genes raise the risk of breast and ovarian cancers in some families. Mutations in these genes (especially in BRCA2) may also increase prostate cancer risk in some men.

Men with Lynch Syndrome (also known as Hereditary Non-Polyposis Colorectal Cancer, or HNPCC), which is a condition caused by inherited gene changes, have an increased risk for several cancers, including prostate cancer.

Diet: The exact role of diet in prostate cancer is not clear, but several factors have been studied. Some studies suggest that men who eat a diet high in animal fat or meat may be at increased risk. In other studies, men who ate the most dairy products — such as milk, cheese and yogurt — had the highest risk of prostate cancer.

Overall, study results have been mixed, and the risk associated with dairy products is thought to be small. The fact remains that men who eat a diet rich in fruits and vegetables may have a lower risk.

Lack of Exercise and a Sedentary Lifestyle: Exercise can help you maintain or lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce your risk of heart disease and other cancers. If you are overweight or obese, work on losing weight.

Risk Myths

Sexual Activity: High levels of sexual activity or frequent ejaculation have been rumored to increase prostate cancer risk. This is untrue. In fact, studies show that men who reported more frequent ejaculations had a lower risk of developing prostate cancer.

Vasectomy: A vasectomy was originally thought to increase a man's risk, but this has since been disproven.

Medications: Several recent studies have shown a link between aspirin intake and a reduced risk of prostate cancer by 10-15%. This may result from different screening practices, through a reduction of inflammation, or other unknown factors.

Alcohol: There is no link between alcohol and prostate cancer risk.

Vitamin E: Recent studies have NOT shown a benefit to the consumption of vitamin E in the prevention of prostate cancer.

Prevention

There are many things that men can do to reduce or delay their risk of developing prostate cancer.

Why is prostate cancer so common in Western culture and **much less so in Asia**? It is believed the major risk factor is diet – foods that produce oxidative damage to DNA.

What can I do to prevent or delay the onset of the disease? There's no sure way to prevent prostate cancer. Study results often conflict with each other and most studies aren't designed to definitively prove if something prevents prostate cancer. As a result, no clear ways to prevent prostate cancer have emerged.



In general, doctors recommend that men with an average risk of prostate cancer make choices that benefit their overall health. *Below are some things that have shown some evidence of lowering your prostate cancer risk.*

Exercise: Exercise can help you maintain your weight, or it can help you lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce your risk of heart disease and other cancers. If you are overweight or obese, work on losing weight. You can do this by reducing the number of calories you eat each day and increasing the amount of exercise you do. If you have a healthy weight, work to maintain it by exercising most days of the week and choosing a healthy diet that's rich in fruits, vegetables and whole grains.

If you don't already exercise, make an appointment with your doctor to make sure it's OK for you to get started. When you begin exercising, go slowly. Aim for 30 minutes of exercise most days of the week.

Reduce Fat: Try to keep the amount of fat you eat from red meat and dairy products to a minimum. In some studies, men who ate the highest amount of fat each day had an increased risk of prostate cancer. While this association doesn't prove that excess fat causes prostate cancer, reducing the amount of fat you eat each day has other proven benefits, such as helping you control your weight and helping your heart stay healthy.

To reduce the amount of fat you eat each day, limit fatty foods or choose low-fat varieties. For instance, reduce the amount of fat you add to foods when cooking, select leaner cuts of meat, and choose low-fat or reduced-fat dairy products. In studies, men who ate the most dairy products — such as milk, cheese and yogurt — each day had the highest risk of prostate cancer. But study results have been mixed, and the risk associated with dairy products is thought to be small.

Make Smarter Food Choices: Eat more fish. Evidence from several studies suggest that fish can help protect against prostate cancer because fish have “good fat” such as omega-3 fatty acids. Avoid trans fatty acids (found in products such as margarine). Try to incorporate tomatoes that are cooked with olive oil, which has

also been shown to be beneficial, along with cruciferous vegetables (like broccoli and cauliflower) into many of your weekly meals.

Eat more fat from plants than from animals. In studies that looked at fat consumption and prostate cancer risk, fats from animals were most likely to be associated with an increased risk of prostate cancer. Animal products that contain fats include meat, lard and butter.

You might consider using plant-based fats instead of animal fats. For instance, cook with olive oil rather than butter. Sprinkle nuts or seeds on your salad rather than cheese.

Soy and green tea are also potential dietary components that may be helpful, as well as broccoli, pomegranate juice, tomatoes and legumes.

What about supplements? Avoid over-supplementation with megavitamins. Too many vitamins, especially folate, may “fuel the cancer”, and while a multivitamin is not likely to be harmful, if you follow a healthy diet with lots of fruits, vegetables, whole grains, fish, and healthy oils, you likely do not even need a multivitamin. Watch your calcium intake. Do not take supplemental doses far above the recommended daily allowance. Taking calcium supplements is fine but avoid taking more than 1,500 mg of calcium a day. Always check with your healthcare team before taking anything on your own.

Seek medical treatment for stress, high blood pressure, high cholesterol, and depression. Treating these conditions may save your life and will improve your survivorship with prostate cancer. A yearly rectal examination and PSA test will also go a long way in early detection or diagnosis.

Relax and enjoy life: Reducing stress in the workplace and home will improve your survivorship and lead to a longer, happier life.



Symptoms Of The Disease

Typically, there are no symptoms in the early stages of prostate cancer and even with advanced prostate cancer there may be no symptoms. Where symptoms do occur, they are often due to non-cancerous conditions, such as benign prostate hyperplasia (BPH).



You should consult with your doctor if you experience any of the symptoms below as these symptoms can also indicate the presence of other diseases or disorders.

CALL YOUR DOCTOR IF YOU EXPERIENCE . . .

- ✓ frequent urination, especially at night
- ✓ weak urine flow
- ✓ an urgent need to urinate
- ✓ urine flow that starts and stops (or is difficult to start or stop)
- ✓ painful ejaculation
- ✓ urination pain or pain in the back, hips or pelvis
- ✓ blood in the urine and/or semen
- ✓ difficulty achieving an erection

Men over the age of 50 often experience urinary problems. An otherwise normal prostate may grow, which can change patterns of urine flow. This enlargement is called benign prostate hyperplasia (BPH) and is generally a normal part of aging – it is not cancer.

Symptoms of advanced prostate cancer may include unexplained weight loss, feeling the frequent or sudden need to urinate, or pain in the lower back/pelvic area or sciatica. These are not always a sign of prostate cancer, but you should speak with a doctor if you have any of these symptoms or other urinary problems.

Psa Progression

We typically refer to Advanced Disease as the state of prostate cancer that has grown beyond the prostate and is unlikely to be cured with surgery or radiation alone. After a man experiences PSA progression after surgery or radiation, hormonal therapy is often given at some point, and often for many years. Some men will not require any hormonal therapy, however, many men's cancer will continue to progress despite the above hormonal treatments and will require more aggressive therapy. This comes in the form of additional second- and third-line hormonal therapies, investigational agents (many are in trials right now from new hormonal therapies to prostate cancer vaccines to bone-targeting drugs), and chemotherapy. See our Advanced Prostate Cancer Guide for more information on progression of the disease.

2. UNDERSTANDING YOUR LOVED ONE'S DIAGNOSIS, TREATMENT CHOICE AND PROGNOSIS

“Your loved one has prostate cancer.” Those words can forever change a caregiver's life. If your loved one has been diagnosed with prostate cancer, you may be struggling to find the right words to comfort him and the best way to support him. You may likewise worry about how your loved one's cancer will affect your life. In addition to affecting how you feel, it may also change your relationship with him as your plans and priorities change. Many caregivers struggle to understand their role. Many questions arise immediately. Doubts and even confusion start creeping in. This is all normal.

Questions you may be asking yourself include:

- What is needed and how can I be helpful?
- How can I best provide support?
- Can I help with learning about the disease?
- Should I take the lead and schedule appointments?
- What questions should I ask the medical team?
- How do I best offer a shoulder to lean on?
- Am I even capable of caregiving?
- Does my schedule allow it? How will I make it all work?

There is no one-size-fits-all answer when it comes to caring for someone diagnosed with prostate cancer. All these concerns and doubts are normal. All caregivers learn with time how they can best support the man they love who has prostate cancer. With time, the patient and loved ones will start to adjust to the cancer diagnosis.

Understanding Your Loved One's Diagnosis, Treatment Choice and Prognosis

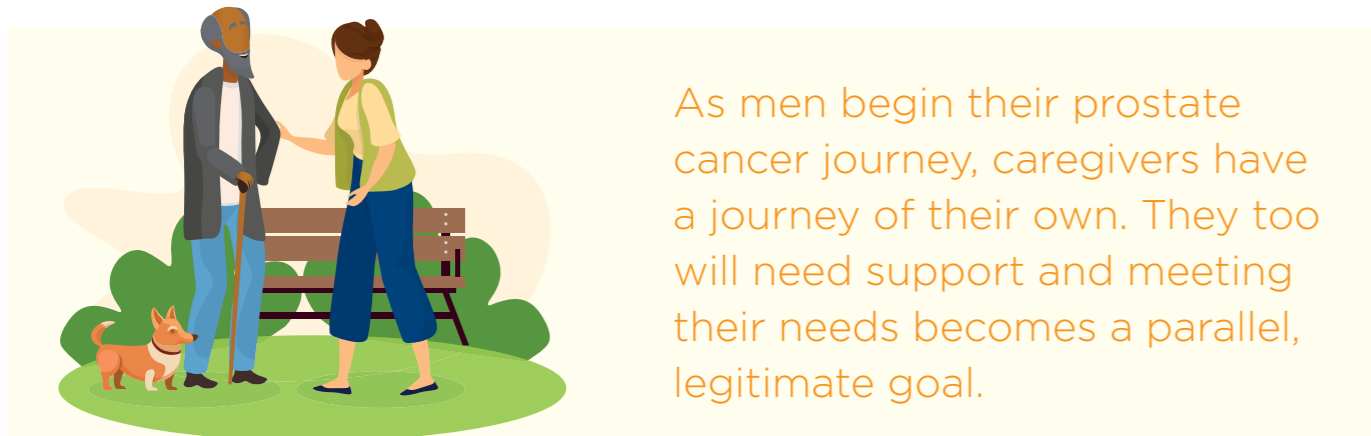
Everyone deals with the shock of a prostate cancer diagnosis differently. Be patient and understanding in view of the circumstances. Let your loved one take the time he needs to work through the news while you provide support. Although your loved one has cancer, the illness is really happening to the both of you. It is okay to let yourself be upset and fearful. Your life is being disrupted in many of the same ways. You are sharing many of the same emotions and concerns. This is a time of change and action. Everyone involved is adjusting to the unexpected and uncontrollable situation that they now find themselves in. With all the activity, some people even go through days of feeling numb and disengaged while others may be sad, edgy, or angry. Emotions may change from minute to minute as each person copes in their own way.

Educate Yourself

There has been much progress made in fighting the disease of prostate cancer, however, it still can be a frightening diagnosis for patients and the people who love them. The journey through treatment is fraught with emotional and logistical challenges as well as medical ones. By being informed and knowledgeable about all aspects of your loved one's disease, you can provide helpful support. Your knowledge will help you talk to doctors, understand different treatment options, and be supportive while your loved one makes decisions.

During this process, it will be important to get accurate, reliable information to be ready when you or others must ask questions or coordinate care. To learn more about prostate cancer, it may be helpful to download the **Vol 1: Prostate Cancer Guide** from the resources center of the website. It provides more in-depth information about prostate cancer, prostate cancer research, prostate cancer treatment and would be a good reference while on the prostate cancer journey with your loved one. Visit www.fightingprostatecancer.org/downloads-guides.

Every situation is different. What you can and should do next will depend on your loved one's personal needs. Here are some general guidelines that could help you provide the kind of support your loved one might need, as well as navigate the challenges that may present themselves on the journey ahead.



As men begin their prostate cancer journey, caregivers have a journey of their own. They too will need support and meeting their needs becomes a parallel, legitimate goal.

Here are some tips to get started in your caregiver role:

- ✓ Go to doctor appointments. Take notes. Research shows that people coping with cancer may not hear everything and miss important information about their care.
- ✓ If asked, help explore treatment options.
- ✓ All prostate cancer treatments have side effects; it is important to discuss with your loved one how you'll be involved in supporting him.
- ✓ Take time to do what nurtures you. Take a walk, talk to friends, read and play music – you are important, and your well-being matters as well.
- ✓ If your loved one is overwhelmed, talk to him and his doctor about counseling or outside help.
- ✓ Remember that both of you will experience a wide range of emotions. Do not suppress these feelings, talk about them together and know that they are normal.

Face the Problem Together

As a caregiver, your loved one and you may find yourselves suddenly trying to decode new terminology, process a diagnosis and evaluate how it will change your lives. You will both be challenged to find constructive ways of dealing with the disruptions and threats posed by cancer as well as with the side effects of medical treatments. In addition, a discussion should be had of how to share the diagnosis. Whom do you tell, who should tell them, and how much should be told to them?

All of this can feel overwhelming. Information and communication are the keys for healthy coping. Learn as much as you can about the illness, educate yourself, forge a good connection with your loved one's healthcare team and ask for assistance and answers when you need them.

It can be tremendously reassuring and comforting to your loved one to know that the two of you are facing the illness together and that your support and involvement will be steadfast and unwavering regardless of what happens.

Here are some of the specific issues that you should try to discuss with each other:

How serious is the cancer?

What is the best treatment, and what are the pros and cons of the different options?

Are there clinical trials to consider, or perhaps complementary or holistic approaches?

What roles or division of labor should we take in learning about these matters?

What should we tell our children, and how can we best help them in dealing with this frightening situation?

Do we tell our friends and family?

What changes do we need to make to the daily routine to accommodate the need for treatments and to deal with side effects?

What does our family need in the way of support and practical help from relatives, friends, and our religious or social communities?

How can we best reach out for the support we need?

Discussion Is Better than Assumption

Sometimes the patient and caregiver have different ideas about handling the diagnosis of prostate cancer. One may want to tell everyone in their address book; the other may need time to process it quietly. Be sure you're on the same page.

Do not assume that you know what your loved one is thinking or feeling about the cancer, or that you know what he needs from you. You might assume your loved one is mostly scared, when in reality he feels sad or perhaps guilty about the consequences of the cancer for you. You might assume he is optimistic, strong, and resilient, when he actually feels vulnerable

and codependent, and may not be ready to admit it. You might think he is open to receiving an offer of encouragement and hope, when he actually just wants you to say, “I agree this stinks, but we’ll face it together no matter what happens.”

The point is to talk with your loved one about his emotional reactions, concerns and worries and to ask what he needs from you. Some of these needs may be concrete or practical: going together to doctors’ appointments, becoming educated about his cancer and the treatment options, handling all the phone calls from friends and relatives, or taking over more household chores. Other needs may be more emotional: being attuned and responsive to what he may be feeling, encouraging him to confide in you, and offering empathy and support during difficult times.

Consider and Understand Treatment Options

Cancer treatments can be tough, with a range of unpleasant or painful side effects. Stay informed, know what to expect and be a strong advocate for your loved one. If you’ve learned all you can and still are uncomfortable with the proposed plan of care, consider getting a second opinion and investigating alternatives.

Prep for appointments. Formulate questions for the doctor with your loved one and bring those questions with you. Take notes during the visit to make sure you remember what was discussed, then sit down together with your loved one afterward and write down thoughts and comments while the conversation is still fresh in your minds.

Manage medications. PCaregivers often help keep track of their loved one’s medications, and cancer patients can take dozens of them a day, each with its own protocol. If you need reminders, set an alarm timed for each dose.

Understand the side effects. Chemotherapy and radiation can have debilitating side effects. Ask doctors what to expect, how to manage the side effects and when to call for medical help. Find out about palliative care, which is focused on alleviating pain and discomfort.

Seek alternative treatments. Your loved one also might consider being part of a drug trial. Visit www.fightingprostatecancer.org/treatment-options to see the recommended treatment options as well as information on new emerging therapies.

There are times when your loved one and you will not agree on decisions that are made. Deciding on a cancer treatment is not a straightforward process. Cancer diagnoses – and treatment plans themselves – can be complex. Doctors present more than one treatment option, and then patients and families must make decisions about which treatment plan to accept. There are times when a patient leans toward one treatment plan, but their loved one or caregiver thinks another plan would be best – as you can imagine, this can create a great deal of distress for everyone. It’s important that you give each other the right to feel the way you do. Try to understand your loved one’s perspective and reserve any judgement. You might even have to talk about how the two of you will “agree to disagree” but still love and care about each other.

Prepare for Common Conflicts

A cancer diagnosis can take a toll on families and caregivers while stirring up all kinds of emotions. Seeing someone you love in pain or fear, especially when you’re frightened too, can be hard. It can be just as hard adjusting to what may be a new interpersonal dynamic, in both interaction and perception. The key, as with so many conflicts, is communicating well and often, avoiding power struggles, and keeping the patient’s best interests in the foreground.



CAREGIVER TIPS: Handling Conflict



ANALYZE THE CONFLICT



ACCEPT CONFLICT
REMEMBER THAT CONFLICT IS NATURAL AND HAPPENS IN EVERY ONGOING RELATIONSHIP



BE A CALMING AGENT

BRING IN A THIRD PARTY

DON'T BE CONFRONTATIONAL: ASK, DON'T TELL

AGREE TO WORK TOGETHER



PRACTICE REFLECTIVE LISTENING



ACCEPT YOU WON'T ALWAYS AGREE WITH THE PATIENT'S DECISION
AGREE TO DISAGREE



MODEL NEUTRAL LANGUAGE

BE WILLING TO COMPROMISE:
JUST BECAUSE YOU ARE IN A CAREGIVING ROLE DOESN'T MEAN THAT YOU SHOULDN'T CONSIDER ANOTHER POINT OF VIEW

Loss of intimacy. This is not always the case, however some people undergoing cancer treatment might lose their sex drive or be physically unable to have sex. If you are the partner, communicate your needs and listen to the patient's needs as well. You may need to redefine what it means for you to be intimate as a couple.

Disagreement over treatment. Sometimes a caregiver is upset when the loved one refuses chemotherapy or other treatments that might prolong life. A nurse or social worker often can help mediate and offer you both a reality check on the treatment's likely outcome. Remember that, ultimately, the decision is the patient's.

Uncertainty about your role. Unless very ill, cancer patients usually can make their own decisions and can dictate how involved they want you to be. Ask how you can be most helpful. Try not to feel hurt if that means backing off for a while. Be open to their point of view and work to understand it.

Family workload disputes. One family member may feel resentment about shouldering most of the caregiving or may be reluctant to relinquish control, causing resentment among those left out. Have an initial family meeting to make plans and distribute tasks. Communicate clearly and often.

Conflict can occur among family members, friends, caregivers and the patient when people cannot see the various perspectives to the challenges at hand. Every conflict requires careful communication practices and level-headedness. During a conflict it's always good to take a deep breath and pause before reacting from emotion.

Getting to Know your Loved One's Team(s)

As you help your loved one manage his prostate cancer, it's important to remember that you are both consumers of health care. A new diagnosis can come with a lot of confusing information and feelings. Many aspects of this disease can affect the way your loved one views himself, the way he interacts with others, and the way others interact with him. There will be some important decisions to be made, based on the doctors recommendations. To help both of you along the way, it's prudent to work with your network of care providers.

In addition to educating yourself about his diagnosis and treatment options, get to know the members of his extended health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

Working with your loved one's healthcare team ensures 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 continue living their life while undergoing treatment.

Be Engaged. An open dialogue with your doctor and healthcare team is important to understand your loved one's prostate cancer diagnosis. Participating in joint conversations with the medical team about your loved one's treatment plan, as well as the sex and intimacy aspect, will help both of you process and deal with the prostate cancer journey. It's important to learn about his individual prostate cancer because it has a direct impact on the treatment options that will be considered.

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, bring the topic to the medical team's attention.

Assess the Medical Team. Are you and your loved one comfortable with your physician? If not — if the doctor seems brusque or disrespectful, or you just aren't communicating well — ask for another provider. The last thing you need is a doctor who adds anxiety or stress to the journey.

Here are a few things that you, as a caregiver, can do to ensure that communication with the extended health care team is as effective as it can be:

Help create a health care journal. Having a health care journal or notebook will allow your loved one to keep all his health information in one place. It should include the names and contact information of the members of his health care team and details of his treatment plan. The journal can also be used as a diary to capture his experiences while undergoing treatment and your experiences as a caregiver, or you can keep a separate caregiving journal, if you like.

Help prepare a list of questions for his next appointment. This list should include your questions and concerns as well as those of the patient. Because the doctor may have limited time, create the list in order of importance.

Accompany your loved one to medical appointments. Be there at the doctor appointments. Even if he has a journal and a prepared list of questions or concerns, it's always helpful for him to have support at appointments. You may think of additional questions to ask, or remember details about his symptoms, treatment or overall quality of life that he may forget. He may just want you there to simply to hold his hand. It will help you feel empowered and prepared for the future to make a treatment plan together.

Write down the doctor's answers. Taking notes will help you and your loved one remember your doctor's responses, advice and instructions. If you have a mobile device, ask if you can use it to take notes or record the discussion, which will help you review the information later.

Important note about communicating with health care professionals. If you want to speak with the health care team without your loved one present, find out about the rules of the Health Insurance Portability and Accountability Act (HIPAA). This law gives patients greater access to their own medical records and more control over how their health information is used. Your loved one will need to give written permission, by signing a consent form, before doctors can share information with you about his medical treatment.

Enlist Support

It's hard to watch someone you care about go through the difficult emotions that may arise with a cancer diagnosis, which can range from denial to sadness to anger. Recognize that you can't do it all. Pushing yourself to the limit will jeopardize your own mental and physical health, not to mention your ability to care for your loved one. **For more in-depth guidance on both practical and emotional support, please reference: Section 5. Supporting the Patient, Section 6. Self-Care and Coping and Section 7. Caregiver Resources & Support Groups.**

Ask for help. Plenty of people in your life would probably be glad to lend a hand if you simply ask. Build a team of people who can help and communicate your needs clearly. Don't forget the little things — a neighbor who can mow your grass or a friend who will pick up a prescription. These add up to more time for you to focus on your loved one and yourself.

Stay connected. Find emotional support. As a caregiver, you may be experiencing anger, fear, grief and resentment. Seek help from a mental health professional, or do some research, there are free counseling or in-person, online and phone support groups led by social workers available. Visit www.fightingprostatecancer.org/resources-1 to find more details on online support communities that may guide you on this journey.

Be aware of your limits. Remember that there are only so many hours in a day. Feel free to say “no” when people ask you to take on tasks (whether they are related to caregiving or not) that you don’t have the time or energy to complete. When you experience a cancer journey it is important to prioritize our time and not spread ourselves too thin.

3. LIVING WITH CANCER — STRATEGY FOR FIGHTING & PREVENTING CANCER WITH HEALTH, NUTRITION & EXERCISE

Maximizing Quality Of Life

As a caregiver of a man with prostate cancer, you may have significant concerns about the overall health and lifestyle of your loved one. However, you are not in charge of what your loved one or patient does. Taking the confrontational approach can often cause problems, especially when it comes to a change in lifestyle. It’s normal to want to encourage or motivate them, but simply demanding that they live a healthier lifestyle isn’t the best option. Perhaps the best, most effective method is being a good role model and leading by example.

If you want to change his diet, 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 or alcohol. Being a role model releases you from having to say a word, and it works. Studies have suggested that having a loved one who is physically active raised the odds by a factor of five that the other person would become more physically active as well.

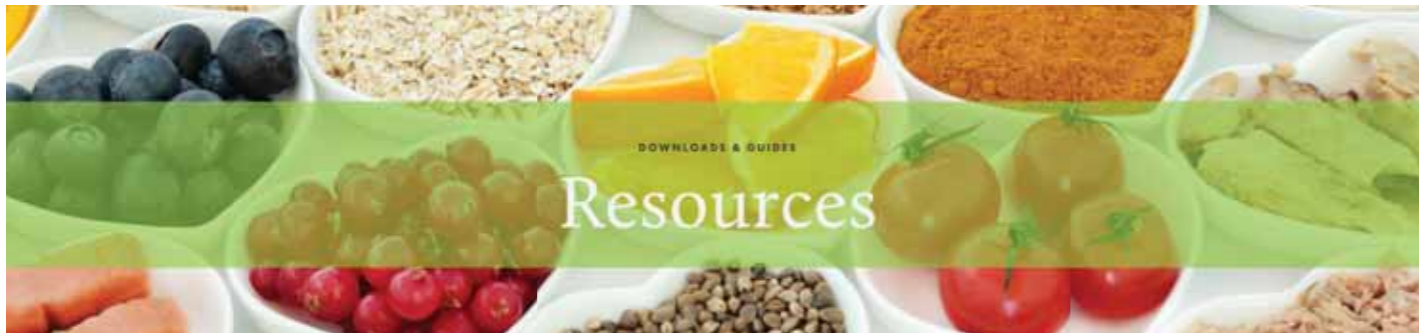
Even if you and your loved one have different opinions about the necessity of a healthier lifestyle, there are several ways in which you can offer encouragement. In order to have the best experience possible, you both need to have your own thoughts and opinions and be autonomous people. Aggressive communication is the wrong approach. At the same time, you do have a right to nudge your loved one in the right direction when it comes to their health and well-being. After all, the health of your loved one matters to you as well and having a healthy long-term relationship has shown a positive impact on medical conditions from cancer to heart disease. Share your feelings and fears about the health of your loved one to start a discussion about exercise.

Here are some tips to support the journey of health and wellness for you and your loved one:

Do Not Nag - Use Gentle Encouragement

If your loved one is reluctant to exercise, make sure to take time to listen, not merely lecture. Nagging or threatening your loved one to exercise or eat right usually backfires. But focusing on your own healthy behaviors may encourage your loved one to do the same. It is surprising how often people make a change after attempts at control stops. It may have something to do with that autonomy mentioned above.

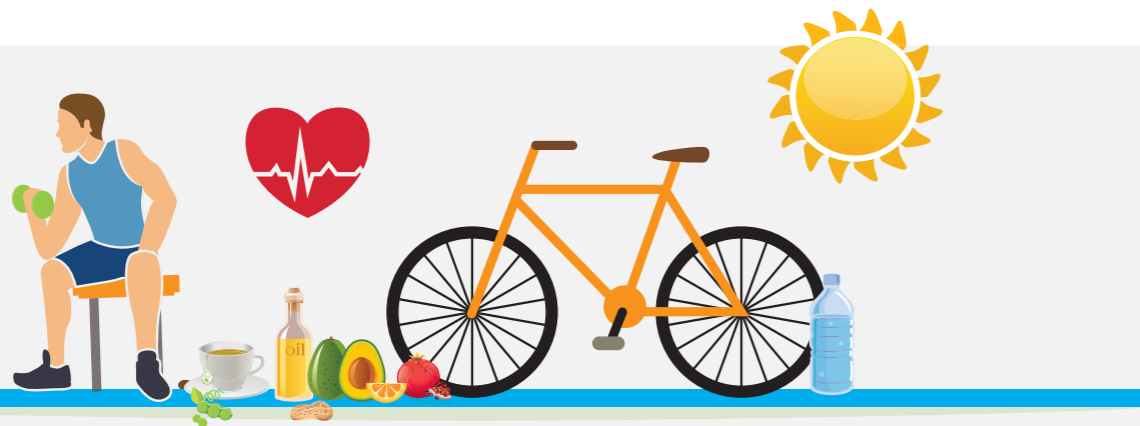
Using gentle, non-demanding encouragement is often the best way to proceed: Plan after-dinner walks, something that is not only a healthy activity but forces you to leave the screens behind and reconnect after a long day. Or perhaps you can invite your loved one to the gym to show them how things work. Just offering a no-strings invitation may be enough to get reluctant patients moving.



Visit the resource center of the IPCF website for prevention tips, support groups, and more!

Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

www.fightingprostatecancer.org/resources-1



FIT PEOPLE HAVE ADOPTED HEALTHY habits and practice them with discipline

In general, doctors recommend that men make choices that benefit their overall health. Below are some things that have shown some evidence of lowering your prostate cancer risk.



EAT FOODS HIGH IN NUTRIENTS, VITAMINS, MINERALS & FIBER
LOW CALORIE FOODS



CANOLA, OLIVE
SAFFLOWER, SOYBEAN
USE HEALTHY OILS

AVOID FRIED FOODS. EAT BROILED OR BAKED FISH. OPT FOR STEAMED, GRILLED, OR BROILED DISHES AT RESTAURANTS

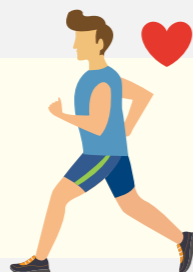


REDUCED FATS IN
RED MEAT & DAIRY



IF YOU INCREASE FIBER,
INCREASE WATER

HEART HEALTHY
IS PROSTATE HEALTHY



PARTICIPATE IN
REGULAR EXERCISE

Be Honest

Rather than getting angry about your loved one's bad habits, try talking about what's really bothering you. Perhaps you're worried about their health and you want a better future. Maybe you simply want to understand why they are so against exercise. Whatever the issue, be gentle and receptive to listening.

Make It Fun

Shouting, "Hey, let's go run 10 miles!" probably isn't going to work. Activities that seem less like exercise, however, such as a bike ride, tennis game, or a walk in the park may be more appealing. Make it about spending time together and having fun rather than about exercise.

Prevention

Visit the resources section for prevention tips, support groups, and more! fightingprostatecancer.org

There are many things that men can do to reduce or delay their risk of cancer and lead a healthier lifestyle. As the caregiver, your health is very important as well, so be sure to monitor your own health data. Tracking overall health and wellness will affect you both positively for years to come.

Why is prostate cancer so common in the Western culture **and much less so in Asia, and why when Asian men migrate to western countries?** It is believed the major risk factor is diet – foods that produce oxidative damage to DNA.

What can a man do to prevent or delay the onset of the disease? There's no sure way to prevent prostate cancer. Study results often conflict with each other and most studies aren't designed to definitively prove if something prevents prostate cancer. As a result, no clear ways to prevent prostate cancer have emerged.

In general, doctors recommend that men with an average risk of prostate cancer make choices that benefit their overall health.

Below are some things that have shown some evidence of lowering prostate cancer risk.

Exercise

Exercise can help maintain both of your weight, or it can help you lose weight. Men who exercise may have a reduced risk of prostate cancer. Exercise has many other health benefits and may reduce risk of heart disease and other cancers. If you or your loved one are overweight or obese, work on losing weight. This can be done by reducing the number of calories you eat each day and increasing the amount of exercise you do. If you both have a healthy weight, work to maintain it by exercising most days of the week and choosing a healthy diet that's rich in fruits, vegetables and whole grains.

If either of you don't already exercise, make an appointment with your doctor to make sure it's OK for you to get started. When you begin exercising, go slowly. Aim for 30 minutes of exercise most days of the week.

Reduce Fat

Try to keep the amount of fat from red meat and dairy products to a minimum. In some studies, men who ate the highest amount of fat each day had an increased risk of prostate cancer. While this association doesn't prove that excess fat causes prostate cancer, reducing the amount of fat you eat each day has other proven benefits, such as helping you control your weight and helping the heart stay healthy.

To reduce the amount of fat intake each day, limit fatty foods or choose low-fat varieties. For instance, reduce the amount of fat you add to foods when cooking, select leaner cuts of meat, and choose low-fat or reduced-fat dairy products. In studies, men who ate the most dairy products — such as milk, cheese and yogurt — each day had the highest risk of prostate cancer. But study results have been mixed, and the risk associated with dairy products is thought to be small.

Make Smarter Food Choices

Eat more fish. Evidence from several studies suggest that fish can help protect against prostate cancer because fish have “good fat” such as omega-3 fatty acids. Avoid trans fatty acids (found in margarine).

Try to incorporate tomatoes that are cooked with olive oil, which has also been shown to be beneficial, along with cruciferous vegetables (like broccoli and cauliflower) into many of your weekly meals.

Eat more fat from plants than from animals. In studies that looked at fat consumption and prostate cancer risk, fats from animals were most likely to be associated with an increased risk of prostate cancer. Animal products that contain fats include meat, lard and butter.

Consider using plant-based fats instead of animal fats. For instance, cook with olive oil rather than butter. Sprinkle nuts or seeds on your salad rather than cheese. Soy and green tea are also potential dietary components that may be helpful, as well as broccoli, pomegranate juice, tomatoes and legumes.

What about supplements?

Avoid over-supplementation with megavitamins. Too many vitamins, especially folate, may “fuel the cancer”, and while a multivitamin is not likely to be harmful, if the patient follows a healthy diet with lots of fruits, vegetables, whole grains, fish, and healthy oils its likely he won't even need a multivitamin. Watch the patient's calcium intake. Do not allow supplemental doses far above the recommended daily allowance. Taking calcium supplements is fine but avoid taking more than 1,500 mg of calcium a day. Always check with the healthcare team before the patient takes anything on his own.

Seek medical treatment for stress, high blood pressure, high cholesterol, and depression. Treating these conditions may save both of your lives and will improve your loved-one's survivorship with prostate cancer. A yearly rectal examination and PSA test for him will also go a long way in early detection or diagnosis.

Relax and enjoy life.

Reducing stress in the workplace and home will improve both of your everyday lives and promote survivorship, leading to a longer, happier existence.

Healthy Body

Preventing cardiovascular disease is an important thing you can do for your loved one's health; regardless of whether they have prostate cancer. This is also important for your health as well. Fortunately, you both can do something to improve heart health—start by increasing regular exercise, eating right and checking your cholesterol and blood pressure.

Watch Cholesterol

It is important to monitor your loved one's cholesterol levels through regular testing to be sure his heart is healthy. Cholesterol test results include total cholesterol level, which is a combination of 3 things:

- LDL (bad cholesterol) +
- HDL (good cholesterol) +
- Triglyceride level (blood fats)

Cholesterol numbers can help predict the risk of heart disease. They can also let you know if lifestyle changes, such as changes in diet or starting an exercise program should be considered.

Talk to your doctor about what your loved one's cholesterol numbers mean. You can also learn more about taking care of both of your hearts from the American Heart Association.

Check Blood Pressure

Have both of your blood pressure levels monitored regularly to ensure good heart health. Blood pressure levels can let you know how well the changes in lifestyle are working. Optimal blood pressure levels may also lower the risk for some abnormal prostate conditions.

Definitions to Understand: **Systolic** is the measurement of blood pressure when your heart contracts. **Diastolic** is the measurement of blood pressure when your heart relaxes and expands.

Blood Pressure Levels

Normal: Systolic: less than 120 mm Hg

Normal: Diastolic: less than 80 mm Hg

At risk (prehypertension): Systolic: 120–139 mm Hg

At risk (prehypertension): Diastolic: 80–89 mm Hg

High: Systolic: 140 mm Hg or higher

High: Diastolic: 90 mm Hg or higher

Permanent Upgrades To Healthy Living

From the moment your loved one is diagnosed with prostate cancer, it's important that he make mindful decisions about his diet and lifestyle. Everyday choices are vital to the success of his treatment and recovery from the disease, and it's a great way to take back some of the control that cancer and its treatment may have had on his life. Additionally, there is growing scientific evidence that suggests healthy diet and lifestyle practices may slow the growth and progression of prostate cancer.

Nutrition To Boost Immunity

Nutrition is an important part of cancer treatment. From changes in taste, to appetite loss and overall fatigue, your loved one may face several challenges. This is common for people living with cancer.

Balancing his diet can be a challenge at the best of times, but when going through a cancer journey it is even more important. The right balance of proteins and calories can help his body stay strong and healthy — before, during, and after cancer treatment.

Watch for key changes in:

Body weight

Muscle mass

Calorie intake

Eating in a healthful manner may help to keep his strength up through a treatment course, provide more energy to spend time with family and friends or be productive at work. It may be important to consider working with a registered dietitian to help with specific nutritional needs.

Check with the Doctor

It's important to talk with his medical team before embarking on any major changes to his diet, including taking any vitamins or supplements. Some vitamins and supplements can affect the prostate cancer treatment.

You Are What You Eat

When you eat healthy food and exercise, the whole body is affected in a positive way. A healthier lifestyle means making smart choices whenever possible. Below are some things to keep in mind regarding nutrition.

Count Calories

To maintain weight control, monitor intake of fat calories.

Read nutrition labels

NO foods high in total fat, saturated fat, & cholesterol

Watch portion sizes: Do not let him overeat. Smaller portions of food are better.

Choose the most nutritionally rich foods from each food group each day — low calorie foods packed with vitamins, minerals, fiber and other essential nutrient.

Eat More Fiber

Eating fiber-rich foods — for example: beans, fruits, vegetables, bran cereals, flaxseed, whole grains, and oats — can help many areas of the body, such as heart, prostate, and digestive health. There are several benefits to adding fiber to his diet, including helping to make him feel full, which can help control weight. It can lower cholesterol, improve blood sugar balance, make bowel movements easier and can reduce the risk of digestive problems.

How much fiber is normal? For a man older than 50 years, 30 grams a day should be the goal..

Flaxseed & Soy

Flaxseed is high in fiber, omega-3 fatty acids, and phytochemicals called lignans. Flaxseed (and its oil) is used as a laxative, to help improve digestive health, relieve constipation, and reduce the risk of heart disease. The addition of soy protein to a diet low in saturated fat and cholesterol may help to reduce the risk of heart disease.

Omega Fatty Acids (Unsaturated Fats)

Omega Fatty Acids are thought to be good for overall health and may be good for prostate health as well. Increase cold water fish, flaxseed, walnuts, soybeans and canola oil. Bake or broil fish and avoid eating fried fish as the trans fats in fried foods are unhealthy. Some studies have shown eating fish 3 times a week lowers the risk of prostate cancer.

Diet

Just a few simple changes in your loved one's daily eating habits can help support healthier living as he recovers from prostate cancer and may even decrease risk of the cancer coming back or getting worse. All these recommendations also apply to maintaining overall health, for the patient and his family. *See the PREVENTION SECTION for eating tips, nutrition guidance, and more.*

Exercise

Exercise is part of a healthy lifestyle for everyone. For prostate cancer survivors, they should exercise as much as physically able, at a pace which is maximal for personal fitness.

For those who can exercise vigorously, walk briskly (3+ miles per hour), and try to add bouts of jogging. Vigorous exercise should include close to maximal effort, in which the heart beats rapidly and the body is sweating. Such activity includes running, vigorous swimming, or fast bicycling.

Research suggests that exercise affects energy metabolism, inflammation, oxidative stress, immunity, and androgen signaling pathways, and is therefore beneficial for men with prostate cancer.

Exercise reduces levels of inflammation. Several studies have shown that vigorous exercise significantly reduced the risk of prostate cancer recurrence, compared with the same volume of exercise at an easy pace.

Lifestyle Behaviors

In addition to diet and exercise, several other lifestyle factors may be associated with prostate cancer risk and progression.

Smoking

Quitting smoking may reduce the risk of dying from prostate cancer and reduces the risk of dying from any cause. The health benefits from quitting begin on the first day after smoking ceases. Recent evidence further suggests that smoking is associated with more aggressive prostate cancer at the time of diagnosis. Furthermore, smokers have a higher risk of prostate cancer progression, including recurrence and metastasis, as well as an increased likelihood of death. Importantly, when compared with current smokers, men who quit smoking more than 10 years ago had prostate cancer mortality risk like those who have never smoked.

Staying Fit

Besides making healthy choices in diet, men being treated for prostate cancer should start an exercise routine. Resistance exercise can help reduce symptoms of fatigue related to prostate cancer treatment. Exercise also strengthens muscles that may have become weakened with hormone treatments.

TIPS FOR HEALTHY FOOD HABITS

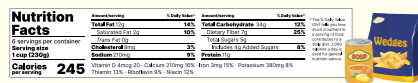
Visit the resource center of the IPCF website for recipes, workouts and mindful strategies to sustain long-term healthy changes!



CHOOSE HEALTHY SOURCES OF PROTEIN & FAT



BOX UP HALF OF THE ENTREE



READ NUTRITION LABELS



SMALLER PORTIONS OF FOOD

Before starting any exercise program, always talk with the team of doctors to ensure that your loved one's program is safe for his physical condition.

There are many reasons why we tend to slow down and become more sedentary with age. It may be due to health problems, weight or pain issues, or perhaps the thought that exercising simply isn't for you. But as we grow older, an active lifestyle becomes more important than ever for both you and your loved one's wellbeing.

Exercise Daily

Exercising for as little as 30 minutes a day can help improve health. Physical active may even be able to reduce some of the side effects related to prostate cancer treatments. Tip: Exercising with friends is both social and motivating. Exercise can help boost energy, maintain independence, protect the heart, and manage symptoms of illness or pain as well as weight.

Daily exercise is also good for the mind, mood, and memory. Becoming active is not just about adding years to life, but about adding life to those years. Exercise not only helps you look better, you'll feel sharper, more energetic, and experience a greater sense of wellbeing.

Lifestyle Assessment

The International Prostate Cancer Foundation has developed a great tool for assessing your baseline health. Both you and your loved one should take it, to discover your health index. You may want to share the results with your doctor. Together, you'll be able to discuss the next steps you should take toward a healthier lifestyle. Take the quiz online, or in the next section of this guide.

Take the Lifestyle Assessment

Your lifestyle is a habit that dictates how fit and healthy you will be. The International Prostate Cancer Foundation has developed a great tool for assessing your baseline health. You may want to print the results and share them with your doctor. Together, you'll be able to discuss what steps toward a healthier lifestyle you should take next. And this baseline will help you know when you are making improvements!

Answer honestly. The assessments purpose is not for guilty feeling or shame. Its purpose is to help you see where you are and if you are in the right mindset for lifestyle changes and commitment. The results may surprise you, but they can also point you to how you can improve both your physical and mental health. Remember the benefits of a healthy lifestyle far outweigh the effort. The body achieves what the mind believes.

12 Easy Questions

Be sure to record your score!

Give yourself 4 points for each a
Give yourself 2 points for each b

Give yourself 1 points for each c
Give yourself 0 points for each d

1. Do You Exercise? (light to moderate activity for 30 minutes)

- a. everyday
- b. once or twice a week
- c. once or twice a month
- d. hardly ever/never

2. Do You Smoke or Use Tobacco Products? (including cigarettes, cigars, chewing tobacco, e-cigarettes)

- a. never
- b. quit years ago
- c. occasionally
- d. everyday

3. How Fit Are You?

- a. very fit, I eat right, no processed foods at all and exercise daily
- b. relatively fit, I eat mostly healthy, some processed foods and exercise weekly
- c. below average, I eat mostly processed foods and sometimes exercise
- d. totally unfit, I eat mostly processed foods and never exercise

4. Are You Overweight?

- a. no, i am where my doctor thinks I should be
- b. yes, but I have started a wellness and fitness plan
- c. yes, i am aware but haven't begun to get fit yet
- d. yes, and I really don't think it's a big deal

5. How Many Meals Do You Eat a Day?

- a. several smaller balanced snack type meals throughout the day
- b. 3 balanced meals with portion control
- c. 3 large unbalanced meals
- d. less than 2 times a day

6. Do You Drink Alcohol?

- a. not at all
- b. seldom
- c. occasionally
- d. everyday

7. How Many Times Do You Eat Out?

- a. zero to two times a week
- b. three or four times a week
- c. five or six times a week
- d. more than 7 times

8. How Many Hours of Sleep Do You Average?

- a. seven or eight
- b. five or six
- c. over nine
- d. less than five

9. Which Statement Best Describes Your Current Feelings on a Healthy Diet?

- a. I buy and prepare a balanced a nutritious diet on a regular basis.
- b. I am currently trying to eat healthy and have a plan in place.
- c. I know that eating healthy would benefit me, but it's hard to stick to it.
- d. The flavor of my food is more important than it's nutritional value.

10. What Do You Do for Leisure and/or Relaxing?

- a. outdoor activities, meditation, exercise, reading, gardening, etc
- b. drinking, eating out, gossiping, etc
- c. movies, surfing the internet, watching tv, etc
- d. free time? I don't have that

11. Do You Suffer from Any Mental Conditions? (*anxiety, depression, insomnia, mood swings, etc*)

- a. never
- b. yes, but i am undergoing treatment and have it regulated
- c. yes, quite often and am just starting to seek treatment
- d. yes, occasionally and I do nothing to treat it

12. Do You Suffer from Any Illness or Diseases? (high blood pressure, diabetes, heart disease, cancer, etc)

- a. no, i get regular check-ups
- b. yes, but I am under doctor care and treatment
- c. yes, it's serious and i am not undergoing treatment
- d. i haven't been to the doctor, I don't know

Lifestyle Assessment Results

Whatever your results, bear in mind that prevention is always the better path. Do not substitute these results for any kind of medical advice or prognosis. This assessment is for understanding the bigger picture of your lifestyle. And will help you decide if you are ready to commit to changing your lifestyle and reaching your goals.

48-35 You are a HEALTH NUT! Congratulations you have some serious discipline. You try your best to live a healthy life and your health is always in tip top condition. You probably see a doctor regularly, and are very proactive about your health. Well done and keep up the good work, but don't forget to engage in some self care and recovery during your fitness journey.

34-23 You are a relatively healthy! Congratulations you live a very healthy and balanced lifestyle. You have a loose plan, and keep yourself mostly to it. Allowing a little liberty to let loose. Don't let yourself slack, you can always set goals and improve to stay on track.

22-11 Although you realize health is important, you aren't living as balanced as you could be. You indulge in life pleasures and temptations very easily, putting your health on the back burner. It's time to be mindful. You can do it. Set an intention. Make a Plan. When you earn your body, you look and feel great!

10-0 Chances are your body has been sending signals of health problems. Your health is low priority and your choices are not conducive to a healthy balanced lifestyle. It's not too late. Take small steps and you'll be on the right path before you know it.

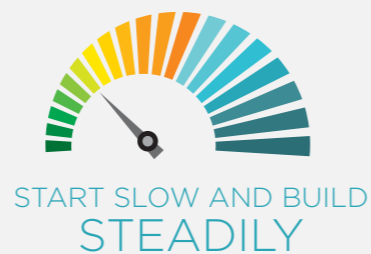


STARTING OR MAINTAINING A REGULAR exercise routine is a challenge at any age

You may not know where to begin, or perhaps you think you're too old or frail. These may seem like good reasons to take it easy as you age, however, they're even better reasons to get moving



GETTING ACTIVE IS ONE OF THE HEALTHIEST DECISIONS YOU CAN MAKE AS YOU AGE, BUT IT'S IMPORTANT TO DO IT SAFELY



DO NOT OVER TRAIN.



AVOID INJURY & PAIN.

Building an Exercise Routine

Do You Hate To Exercise?

Do you or your loved one hate to exercise? You're not alone if you dislike exercise. Or maybe you just think that exercise is boring. The good news is, you don't have to exercise until your soaked in sweat or every muscle aches to make a big difference to your health. Think about activities that stimulate joy and how you can incorporate them into an exercise routine:

- Listen to music, a podcast, or an audiobook while you walk.
- Get competitive while playing tennis.
- Take a dance class.
- Take photographs or birdwatch on a nature hike.
- Meet new people at a yoga class or fitness center.
- Watch a favorite movie or tv show while on the treadmill.
- Chat with a friend while stretching or walking.
- Play golf. Leave the Cart. Walk the Course.
- Walk or play with your pet - (no pet? Volunteer at a shelter or rescue).
- Find an exercise buddy, try activities you've never tried before.

Still hate the idea? Change your perspective, sometimes a change of habit is necessary. Try the ideas below. These are questions you can answer alone, or you can use them to open a dialogue with your loved-one.

Is Something Holding You Back? Identify what it is you dislike. Is it the exertion, the sweating, the societal implications of fitness or body issues? Pay attention to your response, but also experiment, with the goal of developing a pleasant routine. Once you identify the part of the process you dislike, you can adjust your routine. For example, if sweating is the issue; choose an exercise that is low impact where you are less likely to sweat, like swimming or ballroom dancing.

Are you Making Excuses? Do you have 10 excuses ready when workout time comes along? Excuses are rationalizations we make to ourselves about people, events, and circumstances. They are invented reasons we create to defend our behavior, to postpone taking action or simply as a means of neglecting responsibility.

Excuses are mainly a means of placing the blame of an internal problem on an external condition. The fact remains that more excuses you make, the harder it will be to motivate yourself. A way to combat this is trying to make goals instead of excuses. People who exercise regularly report that they come to rely on it and crave more. You could possibly join that club—once you get started, but first you'll need to find exercise that works well for you.

Tailor it to Personality, Make It Fun Just because it's fun and has a social element doesn't mean it can't "count" as exercise. There is no such thing as "real" exercise. A huge array of activities can make it possible for everyone to find a routine that they genuinely enjoy. Enjoyment will make it easier to turn activities into routine exercise.

Make It a Non-Negotiable Part Life Whatever the activity, make sure it works for these three things: lifestyle, routine, and budget. Schedule it into your daily life as a non-negotiable, like brushing your hair or dressing, so that it's harder to break from the routine than it is to stick to it.

Do What You Love You should exercise enough to achieve or maintain a healthy weight. A good way to get started is to find exercises or activities that you enjoy, such as: yoga, powerwalking, swimming, riding a bicycle, dancing, gardening, etc. The important thing is to stay active and keep moving, without overdoing it. A good rule is to exercise enough so you breathe hard but are still able to carry on a conversation.

Make a strategic exercise plan and remember: Don't start with something big. Instead, start with what feels good. That's the best recipe for success!

A Balanced Exercise Plan

Mixing different types of physical activity helps both of you to keep workouts interesting and improve overall health. The key is to find activities that are enjoyable to you or your loved one—based on the four building blocks of fitness. These are: balance, cardio, strength & power training, flexibility.

Balance maintains standing and stability, whether stationary or moving around. Yoga, Tai Chi, and posture exercises will aid in having confidence with balance.

Cardio gets the heart pumping. Helps lessen fatigue and shortness of breath. Promotes independence by improving endurance. Includes walking, stair climbing, swimming, hiking, cycling, rowing, tennis, and dancing.

Strength & Power Training is repetitive motion using weight or external resistance from body weight, machines, free weights, or elastic bands. Strength training helps prevent loss of bone mass, builds muscle, and improves balance—both are important in staying active and avoiding falls. Power training can improve your speed. Building strength and power will help you stay independent and make day-to-day activities easier such as opening a jar, getting in and out of a car, and lifting objects.

Flexibility helps your body stay limber and increases your range of movement for ordinary physical activities. This can be done through stationary stretches and movement to keep your muscles and joints supple and less prone to injury. Yoga is an excellent means of improving flexibility, as well as water aerobics/sports, walking and Qi Gong.

Experiment with Mindfulness Instead of zoning out when you exercise, try to focus on how your body feels as you move — the rhythm of your breathing, the way your feet strike the ground, your muscles flexing. Staying conscious is key. You'll improve your physical condition faster, be able to better help to relieve stress and anxiety, and more likely to avoid accidents or injuries.

Commit to an Exercise Schedule Follow a regular schedule for at least 3 or 4 weeks so that it becomes habit. This is much easier if you find activities you enjoy.

Recovery & Self Care

Recovery after exercise is essential to muscle and tissue repair and strength building. This is even more critical because aging and cancer treatments change the body. Keep this in mind when building your exercise plan, pace out your sessions well. Don't feel guilty about taking time out to recover. Limited research reports suggest that with increasing age muscles tend to recover more slowly after a bout of exercise, whether it is strength or endurance training. Therefore, rest and hydration are essential after exercise, especially as aging sets in.

Here are some tips on how you can aid the body in recovery.

Drink Water.

Eat healthily both before & after exercise.

Consume 30-40 grams of high-quality protein after exercise.

Drink a glass of milk or eat a handful of nuts after exercise.

Give muscles a day off to recover between workouts.

Get serious about pre-workout nutrition.

Don't skip the stretching.

Eat potassium-rich foods.

Focus on quality sleep.

Get a massage.

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. For more in-depth guidance on taking care of yourself *reference: Section 6. Self-Care and Coping.*

Rest & Relax

The most important thing for your loved one's cancer treatment and exercise recovery is for him to listen to his body. If he is feeling tired, sore or notices decreased performance, he may need more recovery time or a break from exercise altogether. Pay attention, in most cases, the body will communicate what it needs, when it needs it. Be sure to listen and be kind to your own body as well; be kind to the body and the body will be kind to you.

Aging & Exercise Safety

Regular physical activity helps us all look and feel younger and stay independent longer. It also lowers risk for a variety of conditions, including Alzheimer's and dementia, heart disease, diabetes, certain cancers, high blood pressure, and obesity. And the mood benefits of exercise can be just as great at 60 or 70 as they were at 20 or 30. Getting active is one of the healthiest decisions one can make as they age, but it's important to do it safely.

Starting or maintaining a regular exercise routine is a challenge at any age. You or your loved one may not know where to begin, or perhaps there is a belief that one of you or both of you are too old or frail. These may seem like good reasons to take it easy as the body ages, however, they're even better reasons to get moving. Becoming more active can energize mood, relieve stress, help manage symptoms of illness and pain, and improve overall sense of well-being. Staying active is what will keep us active in the long run. Maintaining health, strength and flexibility is simpler than recovering them. Additionally, regular exercise can build strength and stamina, prevent loss of bone mass and improve balance.

Benefiting from the rewards of exercise doesn't have to involve strenuous workouts, it's about adding more movement and activity to your life, even in small ways. No matter your age or physical condition, it's never too late to get your body moving, boost your health and outlook, and improve how you age. Getting active is one of the healthiest decisions you can make as you age, but it's important to do it safely.

Get medical clearance your healthcare teams before starting an exercise program, especially if either of you have preexisting conditions. Ask if there are any activities that should be avoided. Additionally, do not add supplements to your diets without consulting your physician(s).

Consider health concerns. Keep in mind how your ongoing health problems affect you or your loved one's workouts. For example, diabetics may need to adjust the timing of medication and meal plans when setting an exercise schedule. Cancer patients undergoing treatment might need to minimize or adjust their routine.

Listen to the body. Exercise should never hurt or make you feel badly. Stop exercising immediately and call the doctor if either of you feel dizzy or short of breath, develop chest pain or pressure, break out in a cold sweat, or experience pain. And put the routine on hold if a joint is red, swollen, or tender to the touch —the best way to cope with injuries is to avoid them in the first place. If you or your loved one regularly experiences pain or discomfort after exercising, try exercising for less time but more frequently throughout the day. If pain continues, consult with a physician.

Start slow and build up steadily. If you or your loved one haven't been active in a while or are undergoing cancer treatment, build up your exercise program little by little. Try spacing workouts in ten-minute increments twice a day. Or try just one class each week. If you're concerned about falling or have an ongoing heart problem, start with easy chair exercises to slowly increase your fitness and confidence.

Do Not Over Train. Prevent injury and discomfort by warming up, cooling down, and keeping water handy. Excessive exercise or heavy training at every session or a lack of rest days will limit you or your loved one's fitness gains and could damage the body.

Stay Motivated

It's easy to become discouraged when illness, injury, or changes in the weather interrupt routine. The good news is that starting an effective exercise routine isn't as unpleasant or difficult as it seems. Start by making the first few steps small, which will stimulate more action and build a foundation. In turn building motivation. Motivation is a mental muscle that works a lot like your other muscles — the more you use it, the stronger it gets.

Here are a few good motivation muscle training tips to get you started:

Create REALISTIC expectations.

Focus on what you can control.

DON'T expect perfection.

Focus on short term goals.

Keep a journal or log.

Reward yourself.

Get support from friends & family.

Try to exercise, even when your regular routine is disrupted.

Even in the best circumstances, it can be difficult to get motivated to exercise, but it's much more difficult when feelings of fatigue set in. Research has shown that physical activity is very important, especially with cancer. It can improve patient function physically as well as their quality of life.

Always remember, too much rest can lead to loss of body function, muscle weakness, and reduced range of motion. So today, many cancer care teams are urging their patients to be as physically active as possible during cancer treatment. Many patients and caregivers are learning about the advantages of being physically active after treatment, too.



Visit the resource center of the IPCF website for prevention tips, support groups, and more!

Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

www.fightingprostatecancer.org/resources-1

TIPS FOR GOOD COMMUNICATION



USE "I" STATEMENTS



ASK YOURSELF
"WOULD I RATHER BE HAPPY,
OR BE RIGHT?"



BE EASY TO TALK TO

REMAIN RESPECTFUL

OF THE OTHER PERSON, EVEN IF YOU DON'T LIKE THEIR ACTIONS



BE OPEN TO LISTEN TO OTHERS' PERSPECTIVE



BE HARD ON THE PROBLEM, NOT THE PEOPLE



KEEP THE CONVERSATION GOING

UNDERSTAND THAT

ACKNOWLEDGMENT AND LISTENING ARE NOT THE SAME AS OBEYING



HAVE AWKWARD CONVERSATIONS IN REAL TIME



YOU CAN USE APPS LIKE HAPPY COUPLE TO IMPROVE YOUR RELATIONSHIP



GIVE THE BENEFIT OF THE DOUBT

4. MANAGING CONFLICT & EFFECTIVE COMMUNICATION

Strategies for Managing Conflict

Since each cancer experience is different, one approach does not necessarily work for everyone. This information serves as a starting point for effective communication and conflict resolution with your loved one. There is no single right way.

Virtually every relationship has experienced some sort of conflict between its participants. Conflict is commonly due to the emotional connections within your relationships. These connections feed reactions to the judgments and input others provide, which can make a person feel out of control, disrespected, or unheard. When this happens, the emotions take over and guide the decisions being made, which can cause a person to act out in hurtful, impulsive ways. It is important to remember that your personal feelings are valid all of the time. However, what you do with them might not be. Before reacting quickly, pause — take time to consider what can be lost if you continue to fight to win.

Conflict in a relationship is virtually inevitable. In itself, conflict isn't a problem; how it's handled, however, can bring people together or tear them apart. Poor communication skills, disagreements, and misunderstandings can be a source of anger and distance or a springboard to a stronger relationship and a happier future.

The fear is that giving in on a particular issue means losing somehow. In turn you can lose sight of the bigger picture and get caught up in the surface instead of focusing on the true root of the conflict. Sometimes humans can unknowingly convince themselves that being vulnerable and communicating the problem is showing weakness. In order to combat this unproductive belief, it may be helpful to look at the conflict objectively.

Conflict is defined as "difference in opinion or some kind of disagreement between two or more parties". Conflicts need to be resolved effectively. It is not only important to resolve the conflict, but also is equally important to ensure that the parties involved in conflict do not unnecessarily end up experiencing trauma during the resolution process. Striking a balance between resolving the conflict to find the compromise and maintaining the emotional wellbeing of the people involved is critical to successfully managing any conflict.

It is important to understand clearly what the conflict is, why the conflict occurred, what the challenges are and the various available methods in resolving conflicts. A starting point to addressing conflict is to analyze it.

Analyze the conflict.

This will help clarify the specific problem more objectively. Some questions that you may ask are:

- What triggered the conflict?
- Who are you angry with?
- Why are you not getting that you want?
- What are you afraid of losing?
- Is your conflict/anger accurate or over-exaggerated?
- How can your conflict be resolved?

Conflicts can be constructive and are good for facilitating growth. Different ways of thinking will help you find ideas and solutions to the problems at hand. Let us approach conflict management with the intention that conflicts can be good for creating growth in our relationships. To manage conflict effectively, there is a need for fostering an atmosphere which empowers everyone involved to think outside the box and encourages them share their feelings, suggestions and opinions without fear. It is always encouraged to resolve conflicts with a very open and collaborative mind. Rise above the personal emotions and prioritize the final goals of the issue at hand.

Five key communication styles for managing conflict:

Smoothing/Accommodating — allowing the other party or parties to satisfy their concerns while neglecting your own. In these kinds of scenarios, one of the parties can take charge and try to smooth the conversation by using nice words and emphasizing on the points of agreements, while playing down on the points of disagreements. This can work as catalyst to break the discomfort between the involved parties. Creating a feeling of trust encourages all involved to come forward and join the conversation.

Withdrawing/Avoiding — not paying attention to the conflict and not taking any action to resolve it. In some situations, one of the parties in the conflict may decide to retract from the discussion. Or one of the parties may decide to completely avoid the conflict by maintaining silence. Open lines of communication are important in addressing any issue keeping a relationship from moving forward. This is not the most effective style, as often avoiding our feelings and concerns can fester and turn into a larger conflict down the line.

Compromising/Reconciling — attempting to resolve the conflict by identifying a solution that is partially satisfactory to both parties but completely satisfactory to neither. Sometimes, for certain conflicts, there will be a need for everyone involved to think of a middle path wherein both parties decide to give up something and identify a resolution and path forward.

Problem Solving/Collaboration — cooperating with the other party or parties to understand their concerns in an effort to find a mutually satisfying solution. Discuss the problem at hand with a very open mind. Allow everyone involved to share their emotions, feelings and concerns. Practicing active listening will be helpful so all parties can feel heard. This creates the space for everyone to open themselves up to collaboration.

Forcing/Competing — using power to satisfy your concerns without regard to the other party's concerns. This is never recommended; it is usually reserved for a working environment hierarchy. (i.e., boss, supervisor who forces a solution) This style is most used when all other avenues have been exhausted or the cancer patient has lost the cognitive ability to participate in a solution to the conflict.

It is important to learn how to navigate your emotions, so that you can express your feelings to your loved one. Collaboration and compromise are the way to deal with important issues, although forcing can sometimes be appropriate if time is an issue, or someone has been determined by professionals to have cognitive failure in some way. For moderately important issues, compromising can lead to quick solutions, but it doesn't satisfy either side, so collaboration is probably better. Accommodation is the best approach for unimportant issues as it leads to quick resolution without straining the relationship or stressing out the patient.

In the next section, there are steps that can be taken to help change the communication style within your relationship dynamic. These can help improve the relationship, so all parties feel they are getting the support they need, while building positive interactions, love and support.

General Tips on More Effective Communication

Good communication with your loved ones involves talking openly and honestly about your thoughts and feelings. It includes sharing experiences, listening to others, and accepting other people's thoughts and feelings without criticism, blame or judgement. Good communication is not easy and does not always come naturally. It requires practice and effort.

Keep eye contact, listen attentively, and avoid distractions when talking. One important way to provide support is to share some silence without needing to drown it out with chatter. Choose your words carefully. Make sure to acknowledge how difficult this experience is for the person.

Effective Communication Tips

Accept Conflict. Remember that conflict is natural and happens in every ongoing relationship. Since conflict is unavoidable, we must learn to manage it. Conflict is only a sign of a need for change and an opportunity for growth, new understanding, and improved communication. Conflict cannot be resolved unless it is addressed with the appropriate individual(s). *Reference the above section for more on managing conflict.*

Practice Active Listening. People often think they're listening but are really thinking about what they're going to say next when the other person stops talking. Try to notice if you do that the next time you're in a discussion.

Active listening means you concentrate on understanding what the other person is saying, rather than thinking about what to say next. Truly effective communication goes both ways. It is a helpful way for you to show that you are connecting to the person's words and feelings. To be an active listener: give your full attention, avoid thinking about what to say next, or hurrying the conversation and forcing it to a conclusion. While it might be difficult, try *really* listening to what your loved one is saying. Don't interrupt. Don't get defensive. Just hear them. For example, restate what your loved one said in your own words. Then, ask for feedback to make sure you understand your loved one's point of view. Then, you'll understand them better and they'll be more willing to listen to you.

Be a Calming Agent. Regardless of whether you are being a sounding board for a friend or dealing with your own conflict, your response to the conflict can escalate or decrease the intensity of the problem. To be calming, provide an objective or neutral point of view. Help plan how you are going to work with the other party to achieve resolution.

Be Specific and Clear. When communicating with people, be very specific. Communicate your feelings, thoughts and opinions, be sure to clarify ambiguous terms that each person may interpret differently. For example, "hurt" could mean either sad or disappointed. People can't read each other's minds, and the only way to effective communication is to be clear, honest and direct. For example, it is more effective to make a request than to blame, shame or judge your loved one. For example, say, "Please don't leave your socks on the floor," instead of "You're so messy."

Use "I" Statements to Describe Your Feelings. Rather than saying things like, "You really messed up here," begin statements with "I", and make them about yourself and your feelings, like, "I feel frustrated when this happens." It's less accusatory, sparks less defensiveness, and helps the other person understand your point of view rather than feeling attacked. Work through how you feel, what the specific problem is and what impact it is having on you.



TIPS FOR INCREASING EMPATHY

- ✓ listen and don't interrupt
- ✓ be fully present
- ✓ tune in to non-verbal communication
- ✓ be encouraging
- ✓ give specific recognition
- ✓ be genuine and consider other perspectives

visit the [ipcf RESOURCES CENTER](#)
to download more tips on healthy communication

I - based statements formula below

I feel (strongest feeling).

When you (objective description of the behavior).

Because (specific impact or consequences).

I would like (what you want the person to do in the future to prevent the problem).

Focus On a Single Topic At a Time. Sometimes it's tempting to bring up past seemingly related conflicts when dealing with current ones. It feels relevant to address everything that's bothering you at once and get it all talked about while you're already dealing with one conflict. Unfortunately, this often clouds the issue and makes finding mutual understanding and a solution to the current issue less likely, and makes the whole discussion more taxing, confusing and even draining on your energy.

Avoid bringing up other topics or old arguments. Do not expect to resolve difficult topics in a single conversation. Agree to continue talking about the subject at another time. Stay focused on the present, your feelings, understanding one another, and finding a solution.

Do Not Rush the Conversation. Take time to decide what you want to say. Give your loved one time as well. Take turns talking, and do not interrupt each other. Give your full undivided attention. Put away or turn off all cell phones or electronic devices. Show respect for those involved, by being fully present and engaged in the conversation.

Own What's Yours. Realize that personal responsibility is a strength, not a weakness. Effective communication involves admitting when you're wrong. If you both share some responsibility in the conflict (which is usually the case), look for and admit to what's yours. Own it, take responsibility. It diffuses the situation, sets a good example, and shows maturity. It also often inspires the other person to respond in kind, leading you both closer to mutual understanding and a workable solution.

Model Neutral Language. When people are in conflict, they use inflammatory language such as profanity, name calling, and exaggerations that escalate the conflict. Restate inflammatory language in a more objective way to help make the information less emotionally laden and more useful for future discussions. Avoid criticism, sarcasm, name calling, and insults. If you become angry or upset, using a calming routine, such as taking a deep breath or leaving the room for a break, can be more helpful than forcing yourself to continue. And taking a break is always better than pushing through and saying things you may not mean.

Respond to Criticism with Empathy. When someone comes at you with criticism, it's easy to feel that they're wrong and get defensive. While criticism is hard to hear and often exaggerated or colored by the other person's emotions, it's important to listen to the other person's pain and respond with empathy for their feelings. Also, look for what's true in what they're saying; that can be valuable information for you. Analyze your own behavior. Do you do any of the things being brought to the conversation?

Look for Compromise. Instead of trying to "win" the argument, look for solutions that meet everybody's needs. Either through compromise or a new creative solution that gives you both what you want most, this is much more effective than one person getting what they want at the other's expense. Healthy communication involves finding a resolution that both sides can be happy with.

Agree to Disagree. Each person has a unique point of view and rarely agrees on every detail. Being right is not what is important. When managing conflict, seeking the "truth" can trap you rather than set you free. For example, consider the differing testimony of witnesses that all see the same event. Truth is relative to the person's point of view.

Take a Time-Out. Sometimes tempers get heated and it's just too difficult to continue a discussion without it becoming an argument or a fight. If you feel yourself or anyone else getting too angry to be constructive, or showing some destructive communication patterns, it's okay to take a break from the discussion until you both cool off. This can mean taking a walk and cooling off to return to the conversation in half an hour, or "sleeping on it" so you can process what you're feeling a little more, as long as you do return to the conversation. Sometimes good communication means knowing when to walk away for a break.

Keep at It. While taking a break from the discussion is sometimes a good idea, always come back to it. If you both approach the situation with a constructive attitude, mutual respect, and a willingness to see the other's point of view or at least find a solution, you can make progress toward the goal of a resolution to the conflict. Unless it's time to give up on the relationship, don't give up on communication.

Ask For Help If You Need It. If one or both of you has trouble staying respectful during conflict or if you've tried resolving conflict with your loved one on your own and the situation just doesn't seem to be improving, you might benefit from getting the point of view from a neutral person. Depending on the severity of the conflict a few sessions with a therapist might be appropriate. Couples counseling or family therapy can provide help with altercations and teach skills to resolve future conflict. If loved one(s) don't want to go, you can still often benefit from going alone.

Communicating with Someone Who Has Cancer

Talking about cancer is challenging because it involves intense emotions. Even those who typically communicate well may have trouble talking about cancer. Discussing a cancer diagnosis may involve topics that couples do not want to discuss. This could include sexual problems, fertility concerns, physical limitations, financial worries, and even death.

Take Your Cues from the Person with Cancer. Ask the person with cancer if they would like to talk about the experience. It is best to allow him or her to decide when to talk and how much to share.

Show Support Without Words. Your body and facial expressions can also convey your message of care and support. Keep eye contact, listen attentively, and avoid distractions when talking. One important way to provide support is to share some silence without needing to drown it out with chatter.

Choose Your Words Carefully. Make sure to acknowledge how difficult this experience is for the person. Carefully choosing what you say can help you show your support without being dismissive or avoiding the topic. For example, it is better to say, “I don’t know what to say” than to stop calling or visiting out of fear.

Here are some things you can say to help show your care and support:

I’m sorry this has happened to you.

If you ever feel like talking, I’m here to listen.

What are you thinking of doing, and how can I help?

I care about you.

I’m thinking about you.

Here are examples of phrases that are unhelpful:

I know just how you feel.

I know just what you should do.

I know someone who had the exact same diagnosis.

I’m sure you’ll be fine.

Don’t worry.

How long do you have?

Communication Strategies for Dealing with Cancer

Your Significant Other Has Cancer

Cancer changes the lives of all people involved; however, it can really put stress on a romantic relationship. The disease affects both of you, and both of you will require support. Work together to talk about and explore treatment options. While the person with cancer makes the final choice about his treatment, it helps strengthen the relationship if both partners have a chance to consider the options together.

Tell your loved one how you are feeling physically and emotionally. Sharing helps your loved one understand your challenges and provides an opportunity for him to support you. Tell your loved one about the specific types of support and encouragement you need. When possible, attend doctor appointments together so you have shared information to go over during such conversations. Choose times to talk when you are both free from distractions and not rushed. Some couples find that scheduling a daily or weekly time to talk works well.

Believe it or not, this experience may even strengthen your relationship. You may see your loved one in more vulnerable and intimate ways as he heals. And facing such a diagnosis also reminds us just how valuable our time together can be. So, make the most of it. Walk a little further, enjoy another movie night on the couch, or time with family and friends.

Strategies for Talking with Your Significant Other or Loved-one with Cancer

Some relationships get stronger during cancer treatment. Others are weakened. Nearly everyone feels more stress than usual when cancer occurs. It helps to know that people express their emotions in different ways. Some like to talk things out or focus on other people. Others like to focus inward by doing things, such as washing the dishes, meditating, or fixing things around the house. These differences can cause tension because each person may expect the other to act the way they would in their place. To reduce stress, it may help to remind yourself that everyone reacts differently. Only you and your loved one know how you feel about this. It is important to say, if either of you don’t feel like your communication needs are being met, you may want to seek help from a counselor or social worker.

Consider practicing what you want to say or writing notes for yourself if you have something difficult to share. This may help you prioritize your values and identify your biggest worries. The sections below may help you think about ways to communicate with your significant other or loved-one.

Do not assume. Assuming you know what your loved one is thinking or feeling or what they will say next can cause major miscommunication. Ask questions if something is unclear.

Maintain confidentiality. It is important to maintain privacy and confidentiality because not only is medical information considered private, it helps to build and develop trust and allows for the free flow of information between you and your loved one. It’s important to acknowledge that your loved one’s personal life and all the issues and problems that they may have belong to them. It is not your place to share private information before your loved one is ready to do so.

Try to See Their Point of View. Primarily, all of us, want to feel heard and understood. We talk a lot about our point of view to get the other person to see things our way. This is understandable, but too much of a focus on our own desires to be understood above all else can backfire. Ironically, if we all do this all of the time, there’s little focus on the other person’s point of view, and nobody feels understood.

For a moment, suspend your own judgment and do your best to see the situation you’re confronting from the perspective of the other. This step is fundamental. It requires you to have empathy and through empathy to widen your understanding of what’s really going on. Others will more likely be willing to listen if they feel heard.

Use caution when asking questions. Phrase your questions carefully and consider the number of questions that you ask in a conversation. People with cancer are often asked many questions by their friends and family members, and it can become tiresome.

Make sure it is okay to give advice. Before you offer any advice, ask if it is okay and be prepared to stop if you are not encouraged to continue. If you feel prompted to make a suggestion, ask for the person’s permission to share it before proceeding. Unsolicited advice may cause unnecessary stress.

Talk honestly about your feelings, both positive and negative. PEotions such as anger, fear, frustration, and resentment are normal reactions to cancer. People often do not discuss these emotions because they fear upsetting each other or feel guilty for having negative thoughts. Hiding feelings creates distance between people and prevents them from supporting and comforting each other. On the other hand, it may be

difficult for your loved one to hear that you feel guilt or sadness. Be aware of the tone of the conversation and be sure to respect your loved one's feelings. It's important to acknowledge all the emotions you both are feeling, not just the positive ones. Do not be afraid to laugh. Humor may help both your loved one and you to cope.

Be honest about your feelings but do not overburden. Communicate any feelings you may be experiencing—such as fear, anxiety, anger, or disbelief — in response to your loved one's cancer diagnosis. But try to be brief in your explanations. Spending too much time expressing the difficult emotions you are feeling may overwhelm and upset your loved one. If you struggle to maintain your composure, give yourself some time away to calm your feelings before talking again. You may find you might need to meet with a counselor to help you process and manage your emotions, as to not burden your loved one.

Talk about topics you typically discuss. You do not always have to talk about cancer. Talking about usual topics may help provide a sense of balance. The intent is not to distract your friend or family member, but to help him maintain usual interests and connections and take a break from difficult conversations.

Talk about the ways you each cope with stress. This helps identify whether you have differing needs in conversation style or action. For example, one loved one may view cancer as a problem to be solved, while the other needs emotional support and validation. Understand that both responses have value.

Focus on the future. Often, dealing with a cancer diagnosis comes with overwhelming emotions and questions. Sometimes, it helps while addressing the heavy topics of treatment, side effects, etc. to focus on future plans. What can you both look forward to once the challenge of cancer is behind you? This technique also lends itself to creating hope and gratitude, which some doctors believe can help aid the immune system in healing.

Get Professional Help. If it is difficult to talk with your significant other or loved one, you may consider meeting with a counselor or therapist. This person can help address communication problems and guide you through difficult conversations, as well as teach you valuable coping methods and tools. Or each of you may choose to find a support group. There are support groups for people diagnosed with cancer as well as for spouses and partners. Support groups provide a setting to learn about other people's experiences communicating about cancer within intimate relationships. *For more in-depth guidance on support groups, please reference: 7. Caregiver Resources & Support Groups.*

The goal of effective communication is mutual understanding and problem solving while pleasing both parties, not 'winning' the argument' or 'being right'. Sometimes it helps to hold hands or stay physically connected as you talk. This can remind you that you still care about each other and generally support one another. This doesn't work in every situation, so be mindful and give each situation the proper consideration.

5. SUPPORTING THE PATIENT AND CAREGIVING BASICS

Caring for a Loved One with Cancer

A cancer diagnosis can affect the emotional health of patients, families, and caregivers. Common feelings during this life-changing experience include anxiety, distress, and depression. Roles at home, school, and work can be affected. It's important to recognize these changes and get help when needed. The diagnosis of a loved one can have a big impact on your life, so make sure you look after yourself. This is important for your sake so that you can support your loved one. *For more in-depth guidance on taking care of yourself, please reference: Section 6. Self-Care and Coping.*

Despite the sadness and shock of having a loved one with cancer, many people find personal satisfaction in caring for a loved one. You may see it as a meaningful role that allows you to show your love and respect for the person. It may also feel good to be helpful and know that you're needed by a loved one.

You might find that caregiving enriches your life. You might feel a deep sense of satisfaction, confidence, and accomplishment in caring for someone. You may also learn about inner strengths and abilities that you didn't even know you had, while finding a greater sense of purpose in your own life.

The caregiving role can open doors to new friends and relationships, too. Through a support group, you can get to know people who have faced the same kinds of challenges. Caregiving can also draw families together and help people feel closer to the person who needs care.

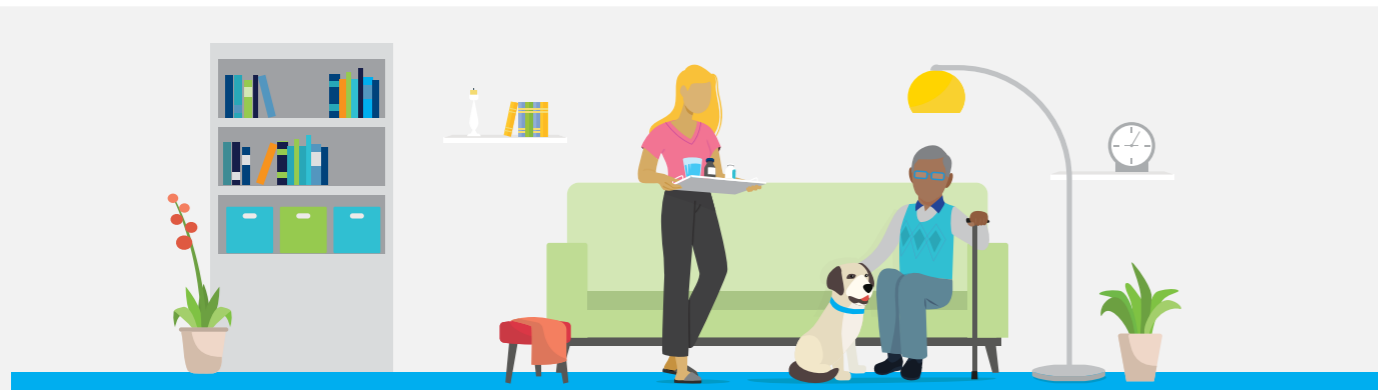
What Is a Cancer Caregiver?

"Caregiver" is a general term referring to anyone who provides care for a person who needs extra help. This could mean a family caregiver, a respite caregiver, a medical caregiver, or a primary caregiver, to name but a few. In the context of prostate cancer, we think of caregivers as unpaid loved ones who give the person with cancer physical and emotional care. They may be spouses, partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they may be the lifeline of the person with cancer.

Caregiving involves a unique combination of performing activities of daily living (ADL), such as meal preparation, dressing, grooming, medication monitoring, transportation and light housekeeping, as well as advocacy, supervision, and organization. It consists of arranging transportation to doctor's appointments, filling prescriptions, paying bills and ensuring a loved one is eating right, among other things. These activities should not be mistaken for home health services, which offer skilled, medical services by licensed professionals, such as nurses and therapists.

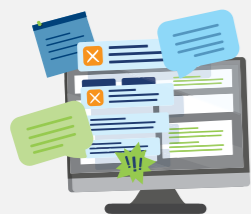
Caregiving can be frustrating and painful. People caring for very sick patients may notice their own feelings of severe sadness and emotional distress. You may feel sadness and grief over your loved one's illness and feel overwhelmed or frustrated as they try to manage many difficult problems.

Caring for someone going through cancer treatment can be demanding but being good at it can give you a sense of meaning and pride. These good feelings can help provide the strength and endurance to continue in the role for as long as needed.



CAREGIVERS: At a Glance

Caregiving spans across all generations, including Boomers, Gen-X, Gen-Z, Millennials, and Silent. An estimated 53 million adults in the United States are caregivers.



61% HAVE
FULL OR PART TIME
OCCUPATIONS



CAREGIVERS
REPORT HIGH LEVELS
OF EMOTIONAL, PHYSICAL
AND FINANCIAL STRAIN



1 IN 3
REPORT FEELING
DEPRESSED

TIPS ON AVOIDING BURNOUT



TAKE CARE OF
YOURSELF



ESTABLISH
A CIRCLE OF SUPPORT OR SEEK
PROFESSIONAL HELP



GET ENOUGH
SLEEP

IT'S OKAY TO SET
LIMITS

EXERCISE, FIND A HOBBY,
OR CONNECT WITH FRIENDS
RECHARGE

EAT HEALTHY
FOODS

What If You Don't Want to Be the Caregiver?

It's quite normal to feel overwhelmed, burdened, and even trapped at times while caregiving. If your family has had troubled relationships in the past, you may wonder "why me?" You may feel that the caregiver role was dumped on you without your consent. You may feel unprepared or even unable to manage the responsibilities and feelings that go with it. You may feel pressure from family members, friends, and members of the cancer care team to provide care, despite having little or no desire or ability to do so.

If you became a caregiver because of other people's wishes, you need to consider how you feel about being pressured into caregiving. Mixed feelings at the onset of this role can lead to a greater sense of frustration later. You should decide on your limits and make them known as soon as you can – before the demands of caregiving become a problem. It's not easy to do this when others resist the change, and it can take a lot of courage to do it. If you know you're going to be met with resistance, talk with your loved one's medical team or social worker first. Or you can ask their doctor about a referral so you can talk with someone about the caregiver issue.

Addressing any problems early can help you and your loved one get the help you need, and if you must, make other plans for care. In situations like this, it might be helpful to find someone to help you with caregiving so that you know from the start that the role will be shared. It also may be better to find someone else to act as the primary (main) caregiver.

People who are "forced" to become caregivers against their natural instincts may do okay for a while, and sometimes that's all that is needed. But caregiving often has a way of evolving into a long-term commitment that gradually becomes more intense. The caregivers might eventually resent their role and could come to resent their loved one's needs as well.

Resentment is a powerful emotion and a key ingredient in caregiver burnout. It eats at the heart of the person carrying the grudge. It builds until it takes on a life of its own, where underlying feelings become hard to hide. Resentment reveals itself in body language. It comes out in one's tone of voice. And, yes, in extreme cases, it can rear its ugly head in the form of neglect or abuse.

Not Everyone Is Cut Out to Be a Caregiver. Each of us is unique, with our own talents and flaws. Most individuals who choose not to be primary caregivers simply don't have the characteristics, time or resources needed to sustain the daily provision of long-term care for a vulnerable adult. Just because someone decides against personally providing total care to a loved one doesn't necessarily constitute indifference or abandonment. Many choose instead to visit, arrange other sources of care, handle financial issues, monitor their loved one's wellbeing and advocate for them. Since nurturing, hands-on care isn't their strength, they turn that type of care over to others who are better suited and qualified to handle it. This could be other willing and able family members, professional in-home caregivers, or staff at a medical care facility.

If you are one of these people who has an inkling that you aren't cut out to be a hands-on caregiver, you are to be commended. Few people can take an honest look at themselves and refuse to compromise who they are no matter how much they may want to.

It is worth mentioning, though, that some people are too hard on themselves. The term "caregiver" means many different things to different people. In fact, some people don't even identify as caregivers even though they alone manage and provide all aspects of a loved one's care.

Should I Hire an Outside Caregiver or a Respite Caregiver?

Some families have the need to hire in-home caregivers to provide quality care for their loved one. A professional caregiver can offer the family a much-needed respite when they take over the cancer-care duties. While in-home caregivers may be trained and/ or certified, they focus mostly on activities of daily living and are not required to perform complex healthcare

related tasks. Programs such as Medicare or Medicaid may cover Home Health Services, but do not usually cover non-medical services. There are some long-term care insurance policies that cover non-medical in-home care services. Review your policy to determine whether in-home care is covered by your insurance.

There are several ways to find in-home care. Referrals from health care professionals and others who have used in-home care may be the best source of quality care providers. You can either hire the caregiver directly as an employee (freelance caregiver) or use an agency. There are many things to consider before deciding to hire a professional or respite caregiver. Below is a guide to help you decide on whether a professional caregiver is right for you and your loved one.

What are the Motivating Factors? The desire for independence and the ability to stay in one's own home are two major motivating factors for hiring a caregiver. While residential care facilities can be a great choice for many, not all people have the desire to leave their current homes and move into a managed community setting. Caregivers often serve as a midway point between complete independence and life in a care facility. Those who need some extra care but still feel comfortable managing most of their own affairs tend to thrive when they're paired with the right caregiver.

Support of Loved Ones. The decision to hire a caregiver is usually a personal one that is governed by several different considerations. In some cases, friends or family members may suggest that a cancer patient hire a caregiver. Alternatively, these loved ones may offer to pay for caregiver services for those who may not be able to afford it. Some may also come to realize that they'd like a little bit of extra help around the house. Everyone comes to hire their caregiver in their own way, but the motivations are always at least a little bit similar.

For loved ones who might be interested in hiring a caregiver for someone else, pay attention to changes in the overall condition of their home or personal appearance. For example, if your mother or uncle was once a person who kept an extremely tidy house and neatly manicured lawn, it may be surprising to suddenly notice that the grass is full of weeds and the house is dusty or even looking a bit dirty. While these kinds of changes can be a sign of something more serious, for many, it's a simple indication that this type of activity isn't as easy as it used to be before a cancer diagnosis and that some extra help may be needed to maintain previous standards. In these situations, a caregiver can be the right person to solve the problem in the long term.

Questions to Ask Yourself. As for whether you should hire a caregiver, there are a few different questions to consider. If you're thinking about hiring a caregiver for yourself, ask yourself, do you feel overwhelmed by the amount of effort you have to put into managing your daily life? If the idea of caregiving for someone else in addition to yourself sounds exhausting to the point that you don't think you can manage, then a caregiver might be able to help.

Similarly, do you often feel frustrated by your own daily tasks, medical needs or work responsibilities? If so, a caregiver might be the right solution. It might be time to bring in some outside help to make your life more manageable.

Hiring a Freelancer or Agency

There are advantages and disadvantages to hiring a freelance caregiver. Families often cite lower cost as the major benefit. However, when hiring a freelance caregiver, there are costs related to being an employer. Work related injuries might not be covered by your homeowner's insurance. Live-in caregivers who use your home as their main residence may be considered a tenant. This may complicate things should you need to terminate this person's service. You should always consult with tax insurance and legal professionals if you choose to hire a freelance caregiver.

Another very important aspect of hiring a freelance caregiver is safety. Has this person been convicted of a crime? What is their work history? Be sure to have the applicant list their experience and training in detail. Request and check the references thoroughly. Employee application forms are available at office supply stores or online and can be used for each potential employee. It is also important to verify that this person can legally work in the United States. A form called the

I-9 should be kept on file for the employee. Fines ranging from \$250 to \$2,000 can be imposed on those who hire illegal immigrants. Also, be sure to have a written agreement with the caregiver to avoid potential wage and labor disputes.

For peace of mind, you may want to use agencies or registries that offer pre-screened caregivers for you to hire directly. Using a screening service does not relieve you of your responsibilities as an employer if you hire the caregiver directly. Agencies and companies who do background checks can be found on the Internet.

The safest way to hire a caregiver is to work with a reputable in-home care agency. In-home care agencies usually offer licensed and bonded staff that perform a variety of tasks. Some find this is better than trying to do it all independently with a freelance caregiver, the experience of caregiving is hard enough without adding more tasks to the family load. While it may be more expensive to hire a caregiver through an agency, you will not be responsible for costs such as accounting, insurance and taxes. When choosing an agency, be sure to ask about what services are provided. Reference the questions below as a guide in this process.

Before you call the home care company, make a list of what you need done. The position should explicitly describe what care services your loved one needs. Be sure to list out your expectations of the caregiver and the agency and put it in writing. Remember, you are the client, and ultimately you must feel comfortable and confident with the caregiver's services.

Interview Questions & Issues to Ask a Freelancer or Agency. When interviewing potential agencies and caregivers, there are many important things to consider:

What services are provided? Caregivers may provide light housekeeping, transportation, meal preparation, medication monitoring, personal care, and assistance with ambulation. Some agencies provide higher levels of care such as incontinence care, heavy transfers, cancer care and Alzheimer's care. Have the agency clearly state in writing what services are provided.

Can they work a schedule according to your needs? Some agencies/caregivers have minimum numbers of hours per shift. Some offer shift rates. Some charge more for holidays, nights and weekends. Ask which holidays are observed by the agency. Be sure to be clear here, you don't want any pop-up expenses to surprise you.



HIRING OUTSIDE CAREGIVER HELP FREELANCER VS AGENCY

- ✓ the agency is responsible for bonds, taxes and insurance
- ✓ be wary of agencies that claim the caregivers are "independent contractors"
- ✓ in most cases caregivers don't qualify as "independent contractors" according to tax and labor laws
- ✓ when using freelancers or independent contractors you could be deemed the employer and assume those responsibilities
- ✓ trying to save costs while violating tax and labor laws can put your family at risk - fines can be levied and penalties or back taxes can accrue

What are the costs? How are payments handled? What is the cancellation policy?

Some agencies/caregivers charge by the hour, while others may charge by the job or shift. You should outline in writing what you are getting for your money. Some agencies/caregivers require a deposit before services begin. Find out what the deposit covers and their refund policy. Additionally, ask about their cancellation policy. Some require advanced written notice of cancellation. Prices can vary widely. The cheapest is not always the best option. It pays to shop and compare.

What is the caregiver's employment status? If the caregiver is the employee of the agency, then the agency is responsible for bonds, taxes and insurance. Be wary of agencies that claim the caregivers are "independent contractors." In most cases, caregivers do not qualify as "independent contractors" according to tax and labor laws. Caregiver fees may seem low, but you could be deemed the employer and assume the employer's responsibilities for taxes and insurance. Trying to save costs while violating tax and labor laws can put your family at great risk. Fines can be levied and back taxes plus penalties can accrue.

Work related injuries may not be covered by your homeowner's insurance. There are no surety bonds that would cover "independent" caregivers for theft, dishonesty or negligence. The same considerations hold true if you hire an individual "freelance caregiver." Check with your legal and tax advisor if you choose to go this route.

What is the agency's/caregiver's track record? How long has the agency been in business? Call the Better Business Bureau to see if the agency has any complaints on file. Obtain and verify references (especially for freelance caregivers).

How much skill and experience do the caregivers have? Does the agency have the skills and experience requirements for their caregivers? What kind of training do they give to their caregivers? Experience usually relates directly to skill. If your loved one has a special need, such as cancer care, be sure the caregiver has experience and knowledge in this area. What is the caregiver's background? Does the agency perform a criminal background check on their caregivers? Is the caregiver open to giving fingerprints? Can they legally work in this country? Do they have a good driving history?

For freelance caregivers, you can do a background check yourself. The Department of Motor Vehicles can provide driving records and the County Courthouse can do criminal records checks. Resources can also be found in the phone book or on the Internet. Be wary of caregivers reluctant to provide background information.

Is the agency bonded, licensed and insured? Ask to see copies of the agency's business or other required licenses, liability insurance policy, Worker's Compensation insurance policy and surety bond. Keep copies for your records in case of a future need.

Is there a cost for assessments? An initial assessment is vital to determining the type of care your loved one needs. Some agencies charge fees for assessments.

Can you interview the caregiver before starting service? You want to find a caregiver you feel comfortable with. Ask about the agency's policy regarding interviewing caregivers. Most offer this for free, while some charge a fee.

What is the caregiver replacement policy? If your worker is sick or quits, are emergency call services available? There should be a plan in place if your caregiver can't work. Ask if you can replace a caregiver if there is a problem and how soon you can have a replacement.

How many caregivers work for the agency? This is important to determine the agency's ability to find a replacement caregiver if needed. Smaller agencies have fewer workers to call for replacements. Larger agencies have more workers to choose from.

You may have more personal questions to ask potential caregivers. Write them down and keep notes on the responses. Finding the right caregiver can be a tedious process, but you will feel better knowing you have done your best. It is a very important decision to bring a caregiver to your home. With the right information, you can determine which agency or caregiver is right for you.

Common Emotions after a Cancer Diagnosis

Feelings of sadness, anger, confusion, and helplessness come with a cancer diagnosis. For the person who has been diagnosed with cancer, it is helpful when friends and family members provide a comforting presence and practical support. It is often difficult for others to know what to say or start a conversation with someone who has cancer. However, staying in touch is always better than staying away.

A cancer diagnosis can affect the emotional health of patients, families, and caregivers. Common feelings during this life-changing experience include mood swings, anxiety, distress, and depression. At any stage after a cancer diagnosis, you and your loved one may experience feelings of loss of control and a range of strong emotions, such as disbelief, fear, sadness, anxiety, disappointment and anger. It's natural to feel loss or grief after receiving a cancer diagnosis for a loved one. At first, the thought of cancer can be overwhelming. Some caregivers and patients might even feel like giving up hope. Having a support system is an important part of dealing with emotions. It's also important to have a supportive health care team who will work emotionally with you and your loved one during and after treatment. *For more in-depth guidance and strategies on coping with your emotions, please reference: Section 6. Self-Care and Coping and 7. Caregiver Resources & Support Groups.*

Many practitioners who treat cancer have determined that a healthy emotional response to a cancer diagnosis includes three phases — initial reaction, distress and adjustment — that will take patients through a typical grieving process.

The initial reaction to a cancer diagnosis is often shock and disbelief, followed by a period of distress characterized by mixed symptoms of anxiety, anger and depression. As your loved one learns about their options and begins to see a treatment plan form, they will enter an adjustment phase. During this early time, they may experience persistent sadness, anxiety or depression, decreased interest in sexual activity, fatigue, difficulty concentrating, remembering or making decisions, insomnia or oversleeping, weight and appetite loss, and restlessness or irritability.

These reactions can be seen as a type of grief — cancer often involves a series of losses, such as the loss of good health, the loss of control, temporary or permanent changes to their appearance, not being able to work or do

their normal activities, changed financial plans, a loss of independence, changed relationships, and a shift in how they see themselves, etc. It usually takes time for both of you to adjust to all these changes. As you and your loved one learn about their options and begin to see a treatment plan form, you will enter an adjustment phase.

Many of these symptoms might be considered unhealthy, but they are a normal part of the process of dealing with a new cancer diagnosis. However, feelings of hopelessness and guilt, or feeling stuck in one of the stages above, may indicate more serious distress. If feelings of sadness and depression grow stronger with time, talk with your healthcare provider. Ask for a reference of a professional counselor who can help you. *For more in-depth information on identifying and working through depression, please reference: Section 6. Self-Care and Coping.*

Dealing with emotions may not be easy at first, it can be difficult to identify and honor what you are feeling. Yet, working through your emotions can help lower stress. This can lead to improved mental and physical health. Many cancer survivors say their experience after a cancer diagnosis also included feelings of hope and connection. For some, it can be a time of reflection and can lead to new goals, growth, and shifting priorities.

COMMON EMOTIONS AFTER A CANCER DIAGNOSIS

STRESS AND ANXIETY

HOPE AND GRATITUDE

LOSS OF CONTROL

FEAR AND WORRY

DENIAL

OVERWHELM

SHOCK AND DISBELIEF

SADNESS AND DEPRESSION

LONELINESS OR ISOLATION

ANGER, GUILT AND BLAME

Caring for Your Children and Household during This Time

Being the caregiver for a loved one with cancer is challenging, often physically and emotionally exhausting. You may wonder how you can cope with a cancer diagnosis while caring for your family and yourself. Start by reconsidering your schedule and to-do list. Also, asking for help when you need it allows you to spend less time worrying and more time with your loved ones. If you have adult children, communicate your struggles to them, maybe they can lend a hand to alleviate some of your stress. If you have younger children, supporting them through this time is not easy, and no one can do it perfectly. Here are some tips and tools to help you and your children cope.

Talk to your loved one about how parenting responsibilities may need to shift during this time. Express your appreciation for his support. Recognize that these added responsibilities can become overwhelming and may lead to frustration. Talk openly about each other's limitations, and brainstorm possible solutions and compromises.

Reevaluate your priorities. Most parents struggle to fit everything into their family's schedule, even without the demands of cancer and cancer treatment. It is important to accept and acknowledge that you do not have the time or energy for everything. Make sure you are realistic about what you can do.

Consider making a list of all that needs to be done. This could include household chores, childcare, and tasks related to your caregiving duties. Then, decide which items are most important for you and which items you can ask someone else to do or just leave undone. Track the family's activities on a calendar that is shared or displayed so everyone can see it. Talk about the plans together at the beginning of each week or the night before each day.

Keep it simple. Reconsider your family's schedule. Schedules can grow complicated quickly in the best of times, and you'll likely have to manage them for yourself, your children, and your loved one. If your children are involved in many activities, ask them to take a break from some. Or allow them to pick which activities they would like to continue. Emphasize that it is better to do fewer activities consistently than to do too many with irregular attendance and preparation. Try to focus only on essential and meaningful events. Build your calendar around activities that you enjoy with your children and tasks that only you can do, like work or school meetings or doctor appointments. Reconsider your own activities and focus on 1 or 2 that are important to you. Do not commit to any new activities until you know you have the time and energy for them. Learn to say no to activities that don't fit either of those categories until you feel you and your family are ready.

Take the helping hand. It is easy to feel overwhelmed, even just covering the essentials. To avoid burnout, it's OK to ask for help — both with mundane tasks and with caregiving duties. Friends and family often want to offer support, but they may need you to tell them what they can do to help. Be specific! These helping hands can go the grocery store, babysit or host playdates, prepare meals, and juggle similar household tasks. When someone offers to help, choose a task from your list that suits the person. For example, you might ask a classmate's mother to drive your child to school each day. Accepting other people's help may be difficult for you at first, but it is often a "win-win" situation. By allowing others to offer support, you can:

- Spend more quality time with your loved one or give attention to your kids.
- Spend time with your loved one, away from cancer-related appointments.
- Give yourself a guilt-free break to take a walk, quiet your mind, or unwind with a friend.

Seek community support. Your local community may offer resources to help you balance caregiving with your family life. Exploring all these resources may be hard for you to manage by yourself. Consider asking a family member or friend to help you.

School guidance counselors may offer your children extra support. After-school programs can also be an option when you have a doctor's appointment or need time for yourself.

If you belong to a **place of worship**, ask about their support programs. Many religious institutions provide financial, physical, or emotional help for parents in need. Many also provide support to non-members.

Charitable organizations in your community may provide everything from childcare and transportation to meals and financial assistance. Oncology social workers, case managers, and your healthcare team can provide referrals. You can also use this list of general cancer organizations.

Ask your children for help. When a loved one has cancer, children often feel powerless to change the circumstances. Asking your children to do chores around the house may help them feel like they are making a difference. Children appreciate being involved in age-appropriate ways. Older kids can babysit or fold laundry, for example, and all kids appreciate scheduled time with you for updates or just time together. Try to keep a regular schedule and routine as much as possible. Most children find comfort in structure. But beware of creating unrealistic expectations for help around the house. This can add to the stress your child or teen is already feeling about the uncertainty of the situation. If you have an adult child, ask them to take on some of the caregiving burden, if they are able.

Consider the following tips when asking your children to help with chores:

Explain that you are going to need some extra help and that everyone in the family needs to pitch in.

Use a chart to help children and teens keep track of their chores. This will keep your expectations clear by establishing a timeline of what tasks need to be completed.

Work together to complete bigger tasks. For example, to clean up after dinner, you might have one child clear the table and another put away the leftovers.

Ask your children to help each other. Teenagers and older children can help with car rides and homework. Younger children can help each other pick up toys or fold laundry.

Build incentives into chores. For example, let your children pick their drink or dessert when they make their own school lunch.

Let your child or teen know that you appreciate his or her help. Say thank you and offer rewards for jobs well done. Rewards may include a family movie night, hot fudge sundaes, or extra screen time.

Remember that you cannot expect your children to be expert cleaners or to do their chores as carefully as you might. Accepting their best efforts will help keep them motivated.

Communicate with your children. Good communication with your children helps everyone in the family cope with whatever challenges lie ahead. Reassure your kids that your plans include them and that you are preparing for "what-if" moments like school pickups or events that you might have to miss. Don't forget to

tell their other caregivers at daycare or school or in your community about your new role as a cancer caregiver, because it affects all your family and because it allows those people to lend an extra hand.

Having a sick parent, grandparent, aunt, uncle, etc. can be emotional and scary for children of any age. As their parent, you are the best judge of how to talk to your children. The first conversation about cancer is often the hardest, but by speaking honestly and helping them express their emotions, you make it easier for them to feel safe and secure. Talk with your kids about cancer and listen to their questions. Let them know that nothing they did caused the cancer. Here are some ways to help your children cope with some of the feelings they may experience during this time:

Writing in a journal or talking with friends and other family.

Drawing pictures for fun or for you or their loved one.

Playing with toys or going on a playdate. Let them know it is fine to take a break from thinking about cancer.

Try to spend relaxed, stress-free time with your children to talk about their hobbies, school life, friends and activities. Help them feel free to talk about fun things.

Take advantage of free and low-cost delivery services. For example, many grocery stores offer online shopping and home delivery. Other items that can be delivered to your home include prescriptions, household items, school supplies, and dry cleaning.

Spend less time in the kitchen. If you enjoy cooking, try doubling recipes and freezing half to save for another meal. Or, keep your meals simple. For example, sandwiches or scrambled eggs can take the place of a more involved meal. You can also take advantage of healthy meal-delivery services or nutritious ready-to-eat and/or frozen foods available at many grocery stores.

Instead of cleaning the whole house, focus on what matters most to you. This could include smaller tasks such as having the dishes done or the toys off the floor. If possible, hire someone to do a more complete cleaning once or twice a month.

Care for yourself. With all the demands on your time, it can be easy to overlook your own needs. Make taking care of yourself a priority so you can care for your family the way you would like. Time spent resting and doing activities you enjoy helps restore your energy. This gives you the strength you need to invest in your family. Try to find time to do something you enjoy, such as meeting with friends or seeing a movie. Do not feel guilty about taking time for yourself when the laundry is not finished or when your child wants a ride to a friend's house. If you find yourself struggling with issues such as fatigue, nausea, pain, or depression, talk with your healthcare team about ways to manage them. *For more in-depth information on self-care, please reference: Section 6. Self-Care and Coping.*

Many times, a parent with caregiving duties feels like he or she must pack more love and fun into every day because the future is uncertain. This puts a lot of unnecessary stress and pressure on both you and your family. Trying to overfill your time together is often tiring for everyone. And it may end up doing the opposite of what you want. Instead, choose smaller, more manageable activities so you can spend quality time with your family.

TIPS FOR PARENTING WHILE CAREGIVING



AIM FOR A BALANCE

BETWEEN ASKING YOUR KIDS TO HELP AND LETTING THEM BE CHILDREN

TALK WITH
YOUR CHILDREN'S SCHOOL

ACCEPT
YOUR NEED FOR HELP

ACCEPT
YOUR CHILDREN'S
RESENTMENTS

NOTICE HOW
YOUR CHILDREN COPE
WITH THE ILLNESS

HELP YOUR CHILDREN

ANTICIPATE HOW THEIR LIVES MIGHT NEED TO CHANGE

LOOK FOR
CHANGES IN YOUR
CHILDREN'S BEHAVIOR

REACH OUT
TO OTHER ADULTS WHO
CAN SUPPORT YOUR CHILD

CREATE
RELAXED TIME WITH
YOUR CHILDREN

MAINTAIN
CONSISTENT ROUTINES
AND LIMITS

REMEMBER THAT

YOUR CHILDREN WILL WORRY AND TRY TO ANTICIPATE THEIR CONCERNS

Being a Caregiver While Still Working

Work can be rewarding in more ways than one. So can caregiving. But together, it's a demanding combination. You may feel like you've got more on your plate than you can handle on some days. Many caregivers struggle to juggle caregiving and their career. The stressors of being a caregiver can take their toll physically, emotionally, and financially. Add to the mix your own children and your career and there's a significant weight to bear.

The way the American healthcare system is currently set up, it is expected that a family member will provide the primary care for a cancer patient. This expectation can cause issues for spouses, adult children and other family members who must be present and productive at work, provide comprehensive care for a loved one, and make time for their own families.

New research has demonstrated that there is a growing population of caregivers who are managing the dual role of working full time and providing full-time care. These caregivers live a double life.

Working family caregivers often manage to stay at work by arranging for a flexible schedule, cutting back their hours, switching to a different type of job, or arranging to work from home. Other caregivers find themselves becoming entrepreneurs — developing tools and products for other caregivers.

Keep work separate. As much as possible, try to take care of caregiving duties in your personal hours, rather than during work hours. Schedule calls and doctor's appointments during your lunch hour and do your research on your loved one's condition after you've gone home for the day.

Have a backup plan. There may be a time when you must leave work in a hurry. Make sure you have a co-worker or two who can step into your role if needed.

Read your employee handbook. Your company may have policies on caregivers, flexible work options, and family leave that may apply to you. You may also have access to an employee assistance program, which can be a helpful resource.

Get organized. You likely have a lot on your to-do list, so now isn't the time to try to keep track of everything in your head. Create a family calendar so everyone knows what's happening and use it to track activities and doctor's appointments. If possible, ask siblings or other relatives to help, and make a schedule that includes everyone.

What kind of support do prostate cancer patients need?

Psychology, or state of mind, has played and will continue to play, a critical role in a patient's cancer journey. From staying positive to managing diet and exercise, overall mental health is a cornerstone in the ongoing treatment and control of prostate cancer. Your loved one may experience new or difficult feelings about his situation. He does not have to face this alone.

Just as with the diagnosis, and regardless of which treatment option chosen, you and your loved one may experience new or difficult feelings about the situation. This is normal.

Living with prostate cancer can affect the way your loved one views himself and it can affect his interactions with the world around him. As always, it's important to check in with your loved one and seek help from his team of doctors, friends and family. Many patients choose to proactively attend support groups with other patients or begin working with a mental health practitioner. Others feel more comfortable connecting one-on-one with another prostate cancer survivor. Everyone is different in terms of what he needs and how these needs can best be met.

The most important thing is to periodically check in with him, carefully reaching out in ways that will work for him. Check with the hospital or cancer center where he receives treatment for referrals to counseling services, often free, for patients living with prostate cancer.

Support and Mental Health

Cancer can certainly make it difficult to feel engaged or connected to the moment. For patients who have been diagnosed with advanced cancer or facing end-of-life issues, their mind can be so full of worry and stress that they struggle to be present and aware of the present moment. Fortunately, there have been many advances and patients are finding alternative ways to cope with both the physical and emotional challenges that come with this disease.

Although it's natural for the prostate cancer patient/survivor and loved ones/caregivers to feel many emotions including anxiety, fear and frustration, it's important to take charge of managing the disease and to recognize that knowledge is power. Below are some tips that can reduce some of the anxiety and confusion that comes with a diagnosis of prostate cancer.

Learn

The International Prostate Cancer Foundation site offers a complete overview of information about the prostate, prostate cancer, its treatment, and educational materials. Visit the *Education Center* or the *Resources Center* at fightingprostatecancer.org to guide you through this journey.

Communicate

A diagnosis of prostate cancer can lead to feelings of fear, anxiety, and depression. Your loved one will need understanding and listening without judgment. Do not pressure him to talk about his feelings before he is ready. Just knowing that you are there for him when he needs you can make a big difference to his sense of emotional wellbeing.

Participate

Ask the patient if he would like support at doctor appointments, tests and treatments. Men often do not like to discuss their health, and your loved one may benefit from your presence as an advocate who can help voice concerns to the doctor. Also, being educated about the disease and the treatment options can help. Be prepared with questions to ask the doctor about the disease and treatment options. Find out what kind of side effects may occur after treatment and how they may affect quality of life for him and impact others.

Find Community

Some caregivers find it helpful to go to therapy or join a support group. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges.

National Association for Home Care & Hospice
nahc.org or 202-547-7424

National Family Caregivers Association
301-942-6430 or 800-896-3650
nfcacares.org

Visit the resource center of the IPCF website for recipes, workouts and mindful strategies to sustain long-term healthy changes!



the benefits of therapy
EXTEND FAR BEYOND PERIODS OF CRISIS

Normalizing some emotions allow patients and caregivers to organize their coping resources and attend to self care more efficiently. Many from both groups also report the opportunity to clarify thoughts & feelings enhanced their coping abilities.



explore
PEOPLE

Build relationships, laugh and connect. Research shows staying connected and laughing can combat sadness.

Some cancer patients report



feelings of
loneliness & isolation.



redefine
COMMUNITY

Being surrounded by friends who love you can increase your happiness & outlook. Join club or support group.

What can I do to support my loved one with his diagnosis?

Many partners, family and friends of men with prostate cancer find that learning more about prostate cancer and its treatment is helpful. It can help you support your loved one when they need to make decisions about treatment. Knowing about treatments can also help you both prepare for the time it might take to recover, and for any side effects.

Some men find it helps to have someone with them at their appointment(s). It's hard to take everything in, ask questions and make notes all at the same time. Having someone else to remember, take notes and to ask questions can be useful. Health professionals involved in supporting your loved one may not be able to discuss his diagnosis, treatment or care with you unless he gives them permission. If he is happy for you to know about these things, then he needs to let his doctor or nurse know. He can request this for anyone – whether that's a loved one, family member or friend.

Doing something to help might ease your own feelings of distress and help you feel more in control. But be aware of your limits and recognize that you don't have to do everything. You will be dealing with your own feelings and emotions and will also need time to talk about them. Try writing down how you are feeling in a journal. Write about something that is worrying you or explore the emotions you are going through. You might find this helps to get things off your chest.

Do something nice for yourself at least once a week. You could have lunch with a friend, visit the library or browse around shops. It doesn't matter what it is, as long as you focus on yourself for a short time. You deserve to have a break and shouldn't feel guilty.

More Ways to Show Support. From diagnosis to treatment decisions to living with prostate cancer, your loved one will need your time and attention but also your support and understanding. This may also mean space – to sort his feelings out and get back on the path to normal.

If he needs space, give it to him. He may not want to talk about his cancer diagnosis and treatment. And that's OK. Recognize that he could have feelings that range from denial and anger to overwhelm, anxiety, and helplessness and let him know you're there when he needs you.

Encourage the person to stay involved. Help your loved one decide how to stay involved in his typical activities and continue old routines. Maintaining normalcy will help many people with cancer cope during a time that includes many unfamiliar experiences. However, a lack of time or energy from cancer or its treatment may prevent some people from usual activities and routines.

You may be able to help your loved one prioritize the activities they want to do and delegate other tasks. For example, you can suggest that your loved one save energy to attend his child's or grandchild's soccer game or school play in lieu of volunteering to help with household chores.

Don't take it personally. Patience is a virtue. Prostate cancer is a lot to deal with. It affects manhood, he may find the side effects embarrassing, and some men may not feel comfortable talking about it. Instead of taking offense, respect those boundaries and feelings.

Show Compassion: Research has shown that a man's sense of masculinity is often tied to his sexual capability. Some men experience physical side effects, like erectile dysfunction, depending on the treatments. Your loved one may experience mood swings from hormones or not want to have sex because they're embarrassed about incontinence. Still, it's important to let your loved one know he's desired. Foster intimacy, even if that simply means massaging each other or cuddling.

Support Your Loved One's True Feelings. Most cancer patients feel pressure to maintain a positive mental attitude, and too often this pressure prevents them from expressing their true feelings. Your loved one might hold back in sharing legitimate fears because he does not want to disappoint or burden you, or because he thinks that negative emotions might jeopardize healing. It is the suppression of fears, sorrow, or anger that could actually jeopardize your loved one's psychological adjustment and immune response. Your loved one probably has good reasons to be worried and upset, as well as to feel hopeful and optimistic. You should try to support and validate both sets of emotions (not only the positive ones).

As with any disease, when prostate cancer strikes, its reach goes beyond the patient. Entire families feel the impact. But because treatment for prostate cancer can affect continence and sexual function, it can hit at the core of romantic, intimate relationships.

How can I help my loved one when he doesn't want to talk about it?

Many men with prostate cancer value being able to talk to those close to them about how they are feeling. It can help get things out in the open and lift their spirits. But some men prefer to cope on their own, and don't want to talk about things, nor want any outside help. You might find this frustrating or upsetting. But remember that he might not see things the same way as you. Even if you think that he needs some practical help or should be talking about his emotions, he might feel that he's coping fine.

Try to help him think about what he wants, rather than telling him what he should do. You can do this by asking questions or saying what you think and asking for his response. Let him know that you are there for him if he needs anything. Be specific about the kind of support you can offer – practical as well as emotional. You might need to give him space to come to terms with things in his own time or deal with things in his own way.

For some men just having family and friends around is enough. You don't have to talk about prostate cancer. Just chatting about normal things and doing some everyday activities together might help. Encourage your loved one to see family and friends and to keep up with social activities and hobbies if he feels up to it.

COPING WITH THE PHYSICAL AND EMOTIONAL IMPACT OF CANCER

You can help your loved one to cope with the impact of cancer and its treatment by:

- ✓ Help him stick to his normal routine as much as possible so he's not consumed with thoughts of his disease or treatment plan.
- ✓ Sit at the back of the movie theater, choose aisle seating in airplanes, find easy access to the bathroom.
- ✓ Become an advocate for prostate cancer research and awareness.
- ✓ Seek out support from other friends and family members.
- ✓ Encourage him to pursue activities that will improve his emotional well-being.
- ✓ Seek out sexual contact and reestablish intimacy.
- ✓ Anticipate and implement changes in his lifestyle due to side effects of treatment
- ✓ Encourage him to do the things he enjoys that are purposeful and meaningful - going back to work, playing with his children or grandchildren, taking trips, golf with friends, etc.
- ✓ Make sure he gets plenty of rest, both mental and physical.
- ✓ Prepare healthy foods that he likes to help keep him at a healthy weight.
- ✓ Encourage him to join a support group. Or join one yourself.

Practical Support

When a loved-one has cancer, you may be wondering the best way to support him. Even though you want to help, it can be hard to know what to say or do. It is important to remember that there are no set rules. Think about the unique dynamic of your relationship and let that guide you as you try to support your loved one. Keep it simple. Remember that often the little things mean the most.

Be creative with the help you offer. Offer specific examples of ways you could help during cancer treatment. This approach is better than, “Let me know if you need any help,” because some have a hard time asking for help. Ideas include running errands, caring for pets, driving the person to an appointment, or picking up children from school. Ask if those suggestions sound helpful. Your help with daily tasks and chores is valuable to a loved-one with a cancer diagnosis. Remember that needs may change, so be flexible in shifting your plans as needed. Let them know that you are available if an unexpected need comes up.

If many friends and family members volunteer to help, you may offer to coordinate everyone’s efforts. Some online communities provide tools to help manage everyone’s involvement.

As mentioned above, some people have trouble receiving practical help. When this happens, you can gently remind them that you do not expect them to return the favor and you do it because you care. While not being pushy, try to suggest specific tasks. There are many ways that caregivers can help with practical matters (the activities of daily living), including:

Household tasks and errands. If you are a caregiver to a spouse or significant other, you may already be handling a large share of household tasks and errands. Consider paying for relatively small services that will take a big load off, such as grocery delivery, a house cleaner or lawn care. If you are a loved-one, offering to shop for groceries, pick up prescriptions or dry cleaning, or offering to drop by the bank or post office can be a big help. Even helping with chores around the house. Think about the little things your friend enjoys and that make life “normal” for them. Offer to help make these activities easier.

Family care. Help your loved one with baby-sitting their children, taking them to and from school and activities, or arrange for play dates. Stay and cook dinner for your loved-one, or if you prefer cook dinner and drop it off. Be sure to ask about dietary restrictions.

Personal care. Men going through prostate cancer treatment may need help with several activities they would normally do themselves, such as bathing or dressing. Ask your loved one to let you know if he wants help with these activities. Some men may prefer that help is provided by a paid helper, rather than a spouse, relative or friend. If that’s the case, ask a member of his healthcare team for recommendations on local home health agencies that can provide these services.

Health care. As a caregiver, you may be involved in some health care tasks that are more typically handled by a nurse, such as administering medication and changing bandages. If you need help with these health care needs, ask the doctor, nurse or hospital social worker about local home health agencies that can send in-home nurses to provide these (and other) services. It is also helpful to aid in the simpler tasks such as driving your friend to an appointment or a support group meeting. Offer to take notes during an appointment or give him company during a treatment.

Organizing medications. Keeping track of prescription and over-the-counter medications can be a challenge under any circumstances. An inexpensive pill organizer (available at most drugstores) allows for the

sorting of medications by day and time of day. There are also free medication reminder apps available for his (or your) smart phone or tablet.

Helping with financial issues: Review your loved one’s insurance policies or Medicare plan to understand what’s covered. If your loved one has private coverage, the insurance company can assign a case manager to explain what services and treatments his plan covers and answer any questions you may have.

Understand what your loved one is entitled to. There are government programs called entitlements that give financial and other aid to people in certain groups, such as those with cancer. A hospital or community social worker can direct you to the governmental agencies that oversee these programs.

Ask for help. If you need help with hospital bills, speak to a financial counselor in the hospital’s business office about setting up a payment plan. If your loved one is in financial difficulty, encourage him to talk to his creditors, as often mutually agreeable arrangements can be made. Reaching out for help early is the most effective approach.

Utilize available programs. For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are many programs to help individuals get medications for free or at a low cost. *For more information, contact the Medicine Assistance Tool, listed in the Resources section of this booklet.*

Emotional Support

Just as cancer affects physical health, it can bring up a wide range of feelings you’re not used to dealing with, for both you and your loved one. It can also make existing feelings seem more intense. Your loved ones emotions may change daily, hourly, or even minute to minute. This is true whether they are newly diagnosed, currently in treatment or done with treatment. This is even true for you as the family member or caregiver. These are all natural emotions during the cancer journey.

The emotional response to cancer will depend on various factors, including the patient’s support system, coping style and perception of illness. As patients struggle with issues of diagnosis and treatment, they may also face the social pressures that come from well-meaning friends who want more than anything for them to be okay.

Often the values you and your loved-one grew up with will affect how you think about and cope with cancer.

For example, some people:

Feel they must be strong and protect their friends and families.

Seek support and turn to loved ones or other cancer survivors.

Ask for help from counselors or other professionals.

Turn to their faith or alternative beliefs to help them cope.

While trying to cope with the day-to-day physical, emotional and financial challenges that accompany living with prostate cancer, it can be very beneficial for the patient and the spouse/loved one/caregiver to talk with others who are having or have had the same experiences.



WAYS TO PURSUE NEW FORMS OF INTIMACY

- ✓ pillow talk and a cuddling
- ✓ write a love letter
- ✓ use vibrators and other aids
- ✓ the use of videos
- ✓ sharing and listening to feelings
- ✓ take a bath together
- ✓ just holding each other in bed
- ✓ massage each other
- ✓ explore new ways of touching
- ✓ holding hands
- ✓ candlelight dinner and a walk
- ✓ laughing together

For some men, just having family and friends around is enough. You don't have to talk about prostate cancer. Just chatting about normal things and doing some everyday activities together might help. Encourage your loved one to see family and friends and to keep up with social activities and hobbies if he feels up to it.

Some doctors think that hope may help the patient's body deal with cancer. So, scientists are studying whether a hopeful outlook and positive attitude helps people feel better.

Here are some ways to build your sense of hope:

Plan the days as you've always done.

Don't limit the things you or your loved one likes to do just because of cancer.

Look for reasons to have hope. If it helps, write them down or talk to others about them.

Spend time in nature. Take a walk. Read on a bench.

Reflect on religious or spiritual beliefs.

Listen to stories about people with cancer who are leading active lives.

Do what works. Think about how you've helped each other feel better during difficult times in the past.

Do whatever works for the both of you.

For more in-depth information reference "Common Emotions after a Cancer Diagnosis" section earlier in this section. For more on coping strategies for the caregiver, please reference Section 6. Self-Care and Coping and 7. Caregiver Resources & Support Groups.

Confronting Sexual Issues

Treatments like surgery, radiation, and hormone therapy remove or destroy the cancer. However, all these treatments can have sexual side effects. Common examples are trouble getting an erection, trouble having an orgasm, loss of libido, incontinence, and fathering children. Your spouse/loved one's cancer and the treatments could have affected his sexual interest, sexual functioning, or feelings of attractiveness. Even without such specific problems, the depression that cancer can cause may reduce libido and sexual functioning. The bodily or mood changes in your spouse/loved one can also cause you to lose interest.

Although every relationship is different, similar themes emerge. Being incontinent or impotent harms a man's quality of life. It can affect his body image and make him feel less attractive. As a result, he may pull away from his partner. Not wanting to push or make the man feel guilty about the loss of sex, spouses/partners may keep silent about their needs. The man may then feel that his lover is no longer interested in him.

Even when couples re-establish intimacy, they can struggle because the experience is often quite different from what they were used to. Sex may no longer be spontaneous, especially if a man is having trouble getting an erection. One or both partners might be turned off if a man leaks or dribbles urine in bed or during foreplay. And all of this can lead to frustration, confusion, and anger.

The key to dealing with these issues is open communication. Because your spouse/loved one might be reluctant to broach these topics, you could take the lead by acknowledging these issues and conveying your desire to face them together. You might also go out of your way to reassure your spouse/loved one of your love and devotion and that your feelings are not motivated just by physical attractiveness or sexual performance, that your main priority is his health and that you continue to desire an intimate physical relationship.

Tips for talking with your spouse/loved one. If your spouse/loved one is feeling less of a desire to have sex or having trouble getting an erection, this may affect your relationship. Try to be as open with your spouse/loved one as you can.

Bring your spouse/loved one with you to doctor's visits. Being part of the conversation may help them understand what you're experiencing.

Listen to your spouse/loved one's concerns, too. Remember that this issue affects both of you.

If sex is a problem right now, it's possible to fulfill each other sexually in other ways. Cuddling, kissing, and caressing are also very pleasurable.

What you can do now. Sexual side effects from prostate cancer treatment are often temporary. While your spouse/loved one's body recovers, you can try a few things to maintain your sex life:

Let the doctor know about any sexual problems occurring right away. Although it can be hard to talk about sex, being open and honest will help your spouse/loved one get the treatment they need.

See a therapist. Couples therapy can help you and your spouse/loved one understand and deal with any sexual issues.

Take care of yourself by exercising, eating a well-balanced diet, reducing stress, and getting enough sleep. Looking and feeling your best will give your self-esteem and mood a boost. Encourage your spouse/loved one to do the same. Staying healthy is beneficial to the body's ability to fight cancer.

Tips for maintaining a healthy sex life. If loss of sexual function occurs after prostate cancer treatment, several options can help a person find pleasure in sex again or return to normal sexual function.

Manage expectations. One choice to make is whether to pursue an active sex life or if the individual and their loved one are ready to pursue new forms of intimacy.

Make time. Set aside time for physical intimacy or stimulation. It may take extra physical and mental stimulation for your spouse/loved one to get and sustain an erection.

Give it time. A loss of interest in sex may occur due to fatigue and other problems relating to prostate cancer and treatment. This disinterest can improve or disappear over time.

Talk. Open communication with your spouse/loved one makes it easier to agree on expectations and share concerns. In some cases, a lower sex drive will not bother the spouse/loved one. Others may enjoy finding new ways to be intimate.

Keep healthy. Getting enough exercise may help boost a person's sex life. Studies show that people with prostate cancer who exercise are more likely to return to an active sex life.

What If the Patient Decides to Stop or Refuses Cancer Treatment?

As a caregiver and loved one of the patient, you may wonder why anyone would make this choice. Maybe the patient has health problems that will make cancer treatment harder or riskier. Maybe they feel that age and life history are at play. Sometimes, religious or spiritual beliefs come into play. There are many reasons why people choose to not get cancer treatment.

Generally, most people make treatment decisions based on their personal perspectives. And some choose not to undergo any cancer treatment. Refusing treatment is a decision that involves not just the medical facts of the case, but the values of the patient afflicted with cancer. This can be very hard for family, friends, and loved ones who may not agree with this choice. But for the most part, people who can make decisions for themselves have the right to refuse any and all treatment. The International Prostate Cancer Foundation strongly encourages patients to make their own informed decisions after having detailed conversations with their physician(s) and care providers.


In fact, knowing the risks and benefits even doctors may even recommend no cancer treatment. In the case of prostate cancer, active surveillance is recommended for the early stages. Which means no treatment will be recommended and the cancer and patient will be monitored with a "wait-and-see" intention. Sometimes, the cancer progresses to a point where it can't be treated, and sometimes the treatment simply stops working. Even when a treatment may extend a person's life, some people find that the side effects of that treatment make life unbearable.

Although it can be hard to accept, sometimes declining treatment is the right decision to make. Given the option, many people would prefer spending their final days enjoying favorite activities with loved ones. That's why it's important to recognize that refusing cancer treatment is not only a medical decision, but a personal decision, as well.

It's okay to ask your loved-one about their reasons for refusing cancer treatment. Be prepared, the answers may be hard to hear. And remember, the choice to refuse treatment is the patient's – no one else's. Often, the reasons make sense and give you a better idea of what's going on inside the patient's mind. It's also acceptable to share what you are feeling, just remain neutral and do not pressure your loved one. You may say something like, "I hadn't thought about it that way, and I'm glad you shared your perspective with me." Or, "I would prefer you to talk to a doctor about treatment options, but I'll support your choice and support you through this time the best that I can."

After a person refuses cancer treatment, it's important to make sure they fully understand their options. You may want to ask the patient to talk with a doctor about the decision. Some will agree to talk with a doctor, and others won't. But don't be surprised if, after talking with a doctor, they still decline treatment. Again, they have the right to make their own choices, just as you have the right to feel the way you do. Try to see it from their position, and continue to offer your support, love and friendship.

Just because your loved-one discontinues treatment for cancer doesn't mean they're giving up. Some with advanced prostate cancer survive for years. These patients can turn to palliative, hospice, and home care designed to help maximize quality of life and minimize symptoms. Many may also be eligible for clinical trials that are exploring new types of cancer treatments.



UNDERSTANDING ADVANCE DIRECTIVES

When the journey gets tough, your family and friends should have your road map. The end of life is never certain. Your wishes should be.


Advance Directive is a general term that refers to the various documents that could include a living will, instruction directive, health care proxy or power of attorney. These documents need updating as medical status changes and decisions are made.

WHAT IS A LIVING WILL OR INSTRUCTION DIRECTIVE?

A legal document that alerts medical professionals and family members to the treatments the patient wants to receive or refuse. This document only goes into effect if specific medical criteria is met and the patient is unable to make decisions.

WHAT IS A HEALTH CARE POWER OF ATTORNEY OR PROXY?

A trusted family member or friend is selected to act as a spokesperson in health care decisions for the patient. A legal document is created that should contain directions about the full range of care the patients wants.



TALK ABOUT IT



WRITE IT DOWN



SHARE IT WITH FAMILY

The included information is not intended to be used as legal advice. Please consult a legal professional before undertaking any form of advanced directive, living will, health care proxy or power of attorney.

Facing the End of Life

We all know that death is a natural part of life and that it will happen to us all one day, but most of us hope that we won't die anytime soon. Realizing that death is close can be frightening and hard to believe. For some people, it may be a relief.

Some people have cancer that no longer responds to treatment and must face the fact that they will soon die. Learning that your loved-one may not have long to live is shocking news, for both of you. Even if you are both aware that the cancer is progressing, hearing those words can be extremely upsetting. This realization can be scary for the person who is sick and for those around him. Your loved-one may be in pain, may be bedridden, or may be confused. Everyone copes in their own way with this news. Emotional reactions may depend on age, family situation, cultural background, religious and spiritual beliefs.

All involved will probably have many strong emotions. After the initial shock, feelings of fear, denial, anger, despair, helplessness and anxiety are common. There is also the concern about how your family and friends will cope – emotionally, physically, socially and financially. The news will mean that you can't live the future you'd planned. It may mean leaving behind a loved one, children, family, friends and pets. You may have questions right away, or you might need time to absorb the news and come to terms with the expected outcome of your loved one's disease.

You will find that you and your loved-one's emotions change, sometimes from day to day or even from hour to hour. This is often part of processing what is happening. How you both respond to these feelings will vary. You may find it hard to think clearly, want to cry or feel completely overwhelmed; you don't need to put on a brave face, these are all natural feelings.

The waves of emotions may not hit in any particular order. And you may be able to work out your own strategies to cope with these feelings. Open conversations and planning ahead can also help the patient, caregiver, family members and friends cope better with the bereavement they may later experience. *For more in-depth information, please reference Section 6. Self-Care and Coping.*

For many, dying is a process that happens gradually. As the body slowly shuts down, energy levels vary and there are good days along with days when the patient can't do much at all. Appetite will reduce, and sips of water or a teaspoon of food here and there may be enough.

As death gets closer, it's common for the patient to have little interest in engaging in the outside world. You may find their attention withdraws from family and friends, and they may sleep more and more during the day.

Near the end, some people may require sedation for symptom management. Many people slip into unconsciousness before dying, although some remain alert almost until the end. Others may have periods of being awake, and then slip back into unconsciousness.

The process of dying and grief can take a toll on you as the caregiver. Be sure you prioritize your own mental and emotional health. Find someone to talk to, perhaps a family member or friend. Also consider seeking professional help through a palliative care specialist or nurse, general practitioner (GP), counselor, psychologist, psychiatrist or spiritual adviser. Other patients and caregivers dealing with end-of-life offer a unique perspective, so you may want to consider joining a support group. *For more in-depth information, please reference Section 7. Caregiver Resources & Support Groups.*

Financial Guidance and Information

The cost of medical treatment is among the many concerns you may have when your loved-one has been diagnosed with cancer. Because bills and debt can add up quickly, people may want to seek financial help soon after being diagnosed with cancer. Although coping with daily financial responsibilities may sometimes seem overwhelming, it is important not to let bills pile up and go unpaid. If you're helping your loved one manage finances or you share the financial responsibility,

determine what health insurance covers. Look into possible sources of help, such as the organizations listed below, which offer limited assistance and guidance.

Oncology social workers, case managers, doctors, and oncology nurses can help or provide referrals to support services and financial resources. In addition to information from social workers and other health care providers, there are also several national and local service organizations that help people with cancer who are facing financial challenges.

Contact these organizations directly to learn more about their specific programs and services, including eligibility criteria.

The Cancer Financial Assistance Coalition (CFAC) is a group of national organizations that provide financial help to patients. CFAC provides a searchable database of financial resources. www.cancerfac.org

CancerCare's financial assistance programs (800-813-4673) provide limited financial assistance for people affected by cancer.

The HealthWellFoundation (800-675-8416) is an independent, non-profit organization that helps insured patients with a chronic, life-altering disease afford their medications.

Family Reach (973-394-1411) is providing these families with the resources they need to keep a roof over their heads, put food on the table and maintain safe, reliable access to cancer treatment.

Advance Directives and Living Wills

Preparing for the end is a dour subject, but when a life is drawing to a close, it's important to set final affairs in order. As unappealing as the topic may be, discussing end-of-life matters with your loved one while they are still relatively well is useful. You both can feel prepared, while determining an outline of how their final years will unfold, ensuring that their wishes will be carried out.

Gather important documents together and store them with a lawyer or in a safe deposit box. This might include insurance records, bank statements, trusts, and a will. Many people also find it useful to create an advanced directive to outline the type of care they want to have going forward, or to select a healthcare proxy to assist making medical decisions. Doing this can help ensure your loved-one's wishes are known and respected, which can be a welcome relief.

Your loved-one may want your help with legal issues. Find out if your loved one has a will. If they don't have a durable power of attorney for health care and financial decisions, ask whether they would like you or someone else they unequivocally trust to take on that role. Ideally, these things are handled well in advance.

Every adult should have an advance directive in which they state the type of health care they do or do not want when they can't make their own decisions. Your loved-one should also appoint someone who can speak for him to make sure his wishes are carried out. These legal documents will avoid any confusion when emotions are running raw.

Each State and County has specific forms for these documents so healthcare professionals can easily recognize the document's purpose. To make things a little less confusing, the below terms are used to describe their advance directive forms. *See the infographic on Advanced Directives on the previous page.*

Advance directive is the general term that refers to the various documents that could include a living will, instruction directive, healthcare proxy or healthcare power of attorney.

A **living will (or instruction directive)** alerts medical professionals and the family to the treatments the patient wants to receive or refuse. In most places, this document only goes into effect if specific medical criteria is met and the patient is unable to make decisions.

In a **healthcare power of attorney (or healthcare proxy)** a family member or trusted friend is selected, someone to make healthcare decisions for the patient when they cannot. In this document, there should be directions to the person selected as your spokesperson (or healthcare agent or proxy) about the full range of care wanted.

6. SELF-CARE & COPING WITH YOUR EMOTIONS

You are best able to provide your loved one with care when you are feeling good about yourself. Providing support for a man with prostate cancer can be very stressful. The caregiver of a man with prostate cancer is often the one listening to his fears, coping with his mood swings, preparing his meals and being “the cheerleader”. Caregiver stress — the emotional and physical stress of caregiving — is common.

Too much stress, especially over a long time, can harm your health. As a caregiver, you’re more likely to experience symptoms of depression or anxiety. In addition, you may not get enough sleep or physical activity, or eat a balanced diet — which increases your risk of medical problems, such as heart disease and diabetes.

You Need to Take Care of Yourself, Too

You also have fears and anxieties. Caregivers can experience not only physical symptoms, like tiredness and trouble sleeping, but also emotional stress, such as worry and depression. This is more likely to be a problem for caregivers who aren’t able to get the support they need, and who don’t take care of themselves — especially those who try to press forward alone, even as their own quality of life suffers.

That’s why it’s important to cultivate your own support system, be it through friends, support groups through local hospitals or online forums for spouses and other people like you. Remember, you can’t be there for your loved-one if you don’t take care of yourself. Be kind to yourself and accept help from others.

Caregiver Stress Syndrome

Caregiver stress syndrome is a condition characterized by physical, mental and emotional exhaustion. It typically results from a person neglecting their own physical and emotional health because they are focused on caring for an ill, injured or disabled loved one. Caregiver syndrome affects people at any age. Because caregivers must be so immersed in their roles, with day and night hours, they often have to neglect their own health. They are experiencing high amounts of stress along with grief since the health of their loved one is declining. In addition, there may be a role shift: the role changes from spouse/spouse, father/daughter, son/mother relationship to a patient/caregiver relationship. This role change is difficult for many people to make, resulting in the manifestation of anger, resentment, and guilt, to name a few.

Many studies show that caregiving causes psychological distress. Emotional stressors aren’t the only issues that arise. Typical physical symptoms include fatigue, insomnia and stomach complaints, with the most common symptom being depression. It is difficult to provide quality care for your loved-one when experiencing this state of stress.

There are several factors that can play a role in caregiver stress syndrome. For some, the lack of boundaries between their roles as a caregiver and a spouse, child, or aunt/sister/brother/son can be challenging. For others, the constant demands and financial management that comes with caring for a person who has a serious illness can result in burnout. Many put unrealistic expectations on themselves to protect others from the burden of caregiving. It’s normal for frustration or overwhelm to set in.



Visit the resource center of the IPCF website for prevention tips, support groups, and more!

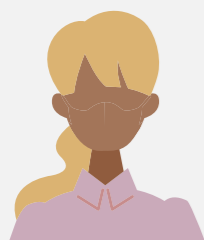
Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

www.fightingprostatecancer.org/resources-1



CAREGIVERS: Risk Factors

People who experience risk factors for caregiver stress can be vulnerable to changes in their own health.



BEING FEMALE



HAVING FEWER YEARS OF FORMAL EDUCATION



HAVING DEPRESSION

LACK OF COPING SKILLS, EMOTIONAL MISMANAGEMENT AND DIFFICULTY SOLVING PROBLEMS



FINANCIAL DIFFICULTIES



SIGNS OF CAREGIVER STRESS



SOCIAL ISOLATION

LIVING WITH THE PERSON YOU ARE CARING FOR

LACK OF CHOICE IN BEING A CAREGIVER

HIGHER NUMBER OF HOURS SPENT CAREGIVING

Over-exhaustion and constant caregiving duties can cause an increase in physical and mental health deterioration. It is thought that a part of the stress of being a caregiver is from how you feel about the job. In other words, if a caregiver does not like or want to be a caregiver, they will inflict more stress on themselves by accepting the role. Caregiver stress syndrome is strongly associated with negative health outcomes. A high number of caregivers suffer from depression and anxiety. Anger and irritability are also common symptoms, and the chronic stress can also lead to high blood pressure, diabetes, and a compromised immune system. Many caregivers have a hard time asking for help. Unfortunately, this attitude can lead to feeling isolated, frustrated and even depressed.

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering.

Watch for these signs of caregiver stress:

Feeling overwhelmed or constantly worried.

Feeling tired, simple tasks are exhausting.

Getting too much sleep or not enough sleep.

Gaining or losing weight.

Becoming easily irritated or angry.

Losing interest in activities you used to enjoy.

Feeling sad or hopeless.

Having frequent headaches, bodily pain or other physical problems.

Abusing alcohol or drugs, including prescription medications.

Recognizing Signs of Depression

Caregiving does not cause depression, nor will everyone who provides care for a loved-one experience the emotions of despair that come with depression. But to provide the best possible care for a loved-one, caregivers often sacrifice their own physical and emotional needs. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion—and then guilt for having these feelings—can exact a heavy toll. The emotional and physical experiences involved with caring for a loved-one with cancer can strain even the most capable person.

People experience depression in different ways; the type and degree of symptoms vary by individual and can change over time. Many with symptoms don't describe themselves as feeling depressed. Some people don't recognize the symptoms in themselves, while others may have a hard time admitting they feel depressed. For some, it is embarrassing to talk about. You may feel like a failure or that people will judge you.

For caregivers, depression is more common than people realize, and it is a natural response to a difficult situation. It is not unusual for caregivers to experience mild or more serious depression as a result of the constant demands they face in their role as caregiver. In general, women caregivers experience depression at a higher rate than men.

Depression is a complex condition with many research studies continually underway. Known contributing factors include genetic characteristics, hormone levels, environmental triggers, certain medications, the effects of living with a major

illness, grief and loss due to the death or pending death of a loved one, having experienced physical or emotional abuse, living with someone with serious depression, and many other factors.

Not everyone will experience depression while caregiving. Everyone has negative thoughts or feelings that come and go, but when these feelings become more intense and overwhelming, it can leave you drained of energy, tearful, hopeless or irritable towards loved ones, it may be a warning sign of depression. Concerns about depression arise when the emptiness and crying don't go away, or when those negative feelings are unrelenting.

Early attention to symptoms of depression through exercise, a healthy diet, positive support of family and friends, or consultation with a trained health or mental health professional may help to prevent the development of a more serious depression over time. If your doctor or therapist thinks that you suffer from depression, he or she may give you medicine to help you feel less tense or refer you to other experts. Don't feel that you should have to control these feelings on your own. Getting the help you need is important for your life and your health. The good news is depression can be treated.

Below are some common signs of depression. If you have any of the following signs for more than 2 weeks, talk to your healthcare provider about treatment. Be aware that some of these symptoms could be due to physical problems, so it's important to talk about them with your doctor.

Emotional signs:

Feeling sad, tearful, empty, hopeless and it doesn't go away.

Feeling emotionally numb.

Feeling nervous or shaky.

Having a sense of guilt or feeling unworthy.

Feeling helpless or hopeless, as if life has no meaning.

Becoming easily agitated or angered — feeling short-tempered, moody or irritable.

Having a hard time concentrating — feeling scatterbrained.

Crying for long periods of time or many times each day.

Focusing on worries and problems.

Excessive time on the Internet.

Trouble focusing, thinking, or planning — as if your head were filled with fog.

Feeling that nothing you do is good enough.

A loss of interest in the hobbies and activities you used to enjoy.

Finding it hard to enjoy everyday things, such as food or being with family and friends.

Thoughts of running away or escaping from the situation.

Thoughts of death or suicide, ideas of how to end your life.

Body changes:

Feeling tired all the time, difficulty being motivated to do anything — Fatigue that doesn't go away.

Changes in eating habits — weight loss and no appetite or cravings with weight gain.

Changes in sleep — such as not being able to sleep, having nightmares, or sleeping too much.

Racing heart, dry mouth, increased perspiration, upset stomach.

Changes in energy level.

Increase in alcohol or drug consumption—including prescription medications.

Neglecting your physical well-being and appearance.

Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic neck and back pain.

The National Institute of Mental Health offers the following recommendations if you are suffering from depression symptoms:

Set realistic goals considering the depression and assume a reasonable amount of responsibility.

Break large tasks into small ones, set some priorities, and do what you can as you can.

Try to be with other people and to confide in someone; it is usually better than being alone and secretive.

Participate in activities that may make you feel better, such as mild exercise, going to a movie or ballgame, or attending a religious, social, or community event.

Expect your mood to improve gradually, not immediately. Feeling better takes time.

It is advisable to postpone important decisions until the depression has lifted. Before deciding to make a significant transition — change jobs, get married, or divorced — discuss it with others who know you well and have a more objective view of your situation.

People rarely “snap out of” a depression. But they can feel a little better day by day.



WARNING SIGNS YOU ARE MENTALLY EXHAUSTED

- ✓ you're easily irritated
- ✓ you feel completely unmotivated
- ✓ you experience anxiety
- ✓ you're having trouble sleeping
- ✓ you feel empty
- ✓ you have almost no patience
- ✓ you start to cry unexpectedly
- ✓ you feel detached from reality
- ✓ you feel numb

Remember, positive thinking will replace the negative thinking that is part of the depression. The negative thinking will be reduced as your depression responds to treatment.

Know Your Limitations

Being a caregiver for any patient or loved one is extremely challenging on both physical and emotional levels. Especially if you have a close connection with the patient, things can sometimes be even more burdensome. It is difficult to provide care for another, and it's not always easy to recognize our limits until we go beyond them. It is important to keep in mind that you have your own limitations as a human being. You need to pay attention to your own needs in order to stay strong and balanced so that you are prepared to provide ongoing care to your loved one. It cannot be denied that caregiving for a loved one takes a lot out of you. Even if you consider yourself to be a strong person inside and out, it is crucial to take time for yourself before you become worn out.

Self-Care: Creating Balance for Yourself

The emotional and physical demands involved with caregiving can strain even the most resilient person. If you're a caregiver, one of the most important things you can do is carve out time to care for your body, mind and soul. That's why it's so important to take advantage of the many resources and tools available to help you create a self-care routine. It has also been reported that cancer patients can even benefit from a regular self-care routine. Remember, if you don't take care of yourself, you won't be able to care for anyone else.

Taking time out to care for yourself can remind you and others that you and your needs are important, too. Having a well-cared-for body can make you feel good about yourself and your life and conveys to others that you value yourself. This can contribute to long-term feelings of well-being.

Make a conscious effort every day. It can be as simple as spending 10 minutes walking around the neighborhood, diving into the latest bestseller or weeding your garden. Every small step toward rejuvenation will benefit you, and, in turn, the loved one in your care. The fact is, if you don't learn how to take a timeout, your frustration is likely to boil over. You'll be less productive; your health could decline and your relationship with your loved one will suffer.

It's so important to make sure you take good care of your body, mind, and soul every day. Learning how to eat right, reduce stress, exercise regularly, and take a time-out when you need it are the touchstones of self-care and can help you stay healthy, happy, and resilient. Consider this list of things you can do for yourself that will build a self-care routine and manage caregiver stress:

Accept help. Be prepared with a list of ways that others can help you, and let the helper choose what he or she would like to do. For instance, a friend may offer to take your loved-one on a walk a couple of times a week. Or a friend or family member may be able to run an errand, pick up the groceries or cook for you.

Set realistic goals. Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists and establish a daily routine. Begin to say no to requests that are draining, such as hosting holiday meals.

Get regular physical activity and set personal health goals. Set goals to establish a good sleep routine, find time to be physically active on most days of the week, eat a healthy diet and drink plenty of water. Regular, moderate-to-vigorous physical activity — even in small increments — can boost your energy level. Exercise reduces stress, helps you maintain a healthy weight, and can keep your blood pressure and cholesterol at heart-healthy levels. Walking is a great way to get started, even if you only walk around the yard.

Monitor your sleeping habits. Caregiving can be emotionally and physically draining, and you should try to get enough sleep. Not getting quality sleep over a long period of time can cause health issues. If you have trouble getting a good night's sleep, talk to your doctor. The Centers for Disease Control and Prevention (CDC) recommends at least seven hours per night for adults. Also, take naps during the day if you need them.

Maintain a heart-healthy diet. A healthy diet will give you more energy. Eating well can help prevent other health problems, as well. If you must “eat on the run” (which can certainly happen), try to choose nutritious snacks.

Make time to find joy. Take time every day for an activity you enjoy, such as reading, walking, crafts, cooking or listening to music. Whatever makes you happy and relaxes you can be therapeutic.

Keep humor in your life. Laughter is good medicine. Try to find humor in your situation. Watch a silly TV program or go out for a movie that that is sure to bring a giggle. Find things to laugh about with the loved one in your care — that person needs joy too.

Get out and about. At least once a week, break out of your routine and go somewhere enjoyable. Visit the local coffee shop, attend church or spiritual events, take a class, visit a friend or just wander around a museum or out in nature. If your loved one needs constant attention, ask for help. It's likely that someone will be happy to give up an hour or two a week so that you can get out and get a breath of fresh air.

Monitor your mental health. It is important to be aware of our mental health. To have a better understanding, track your levels of stress, anxiety and depression. Awareness of how your mental health changes over time will help you keep things in check. If you feel you don't have a handle on your mental health, don't be afraid to contact a licensed professional. Talk therapy is a great way to express your emotions in a safe environment. And with today's technology, talk therapy has never been easier to access.

Watch out for depression. The demands placed on you as a caregiver can be difficult and stressful. Be vigilant for signs of depression. Often depression symptoms can be managed with the help of talk therapy or medication. *For more in-depth information, please reference Recognizing Signs of Depression in the above section.*

Take care of business. Keep your checkbook and accounts balanced, work when you need to and don't stop planning for the future. If you allow yourself to be totally immersed in your caregiver responsibilities alone, it'll be harder to re-integrate into life later. Keep living.

Keep medical and dental appointments. Do all you can to keep your health maintained. If you're having health challenges, you won't be able to show up for your loved-one. Ask for help when you need it so you can get away and take care of your needs.

Think positive. Take time every day to refresh your mind. Acknowledge the limitations and make peace with them. Let go of guilt. Pat yourself on the back for the job you're doing. If you're feeling guilty or angry, take a break.

Stay connected with the outside world. Don't allow yourself to become isolated. Stay connected with family and friends, even if it's just by phone or online. Talk to friends about something other than cancer and your role as a caregiver.

12 ACTS OF SELF-CARE FOR CAREGIVERS



STAY SOCIALLY
CONNECTED



ADD LAUGHTER
AND HUMOR TO YOUR LIFE



SEEK AND ACCEPT
SUPPORT

IDENTIFY, ACKNOWLEDGE AND LEARN FROM YOUR EMOTIONS



REDUCE
PERSONAL STRESS



ATTEND TO YOUR
OWN HEALTHCARE NEEDS



PRACTICE
SELF-COMPASSION

GET PROPER SLEEP NUTRITION AND HYDRATION

PARTICIPATE IN PLEASANT, NURTURING ACTIVITIES



CONNECT
TO NATURE



TAKE GUILT FREE
TIME FOR YOURSELF



CREATE
AN EXERCISE PLAN

Strategies for Coping with Your Emotions

Taking care of a loved one can be a positive experience, but it can also feel like a full-time job, and be very stressful. This is even more challenging if you have other significant responsibilities, like working, raising children, or caring for your own health. Many caregivers tend to put their emotions aside to focus on the practical. And in general, most people try to avoid emotional pain. But if we can face our emotions and learn to cope with them, we can achieve emotional balance. Emotional balance promotes physical health and is a prerequisite for personal wellbeing and growth.

Emotional balance occurs when we allow ourselves to feel whatever comes up, without feeling stifled or overwhelmed, and learn to accept our feelings without judgment. This balance is the ability of the mind and body together to maintain equilibrium and flexibility in the face of challenge and change. Our mind is made up of our thoughts and emotions, and our happiness depends on us remaining in a balanced mental/emotional state. Everyone experiences negative thoughts and emotions but if we stay in that state for too long, we can lose the ability to return to our balanced, neutral position.

We might find ourselves trapped or locked in any number of negative states— anger, fear, worry, dissociation, self-sabotage or depression, agitation, impulsivity, anxiety, panic attacks and sleep trouble, lack of drive and motivation, or poor concentration. These stuck emotions run just below the level of consciousness, intangible yet often overwhelming. These uncomfortable emotions can dominate our thinking process and give rise to feelings of overwhelm and inactivity that impair our ability to be at our best.

There are things both you and your loved-one can do to help both of you cope with your emotions. Below are some strategies that when done with routine can help you achieve emotional balance:

Express Your Feelings and Get Emotional Support. Caregiving is hard work that can affect your emotional well-being. Taking care of yourself includes coping with many of the feelings that arise as you care for your loved one. Many have found that when they express strong feelings like anger or sadness, it is easier to let go of them. Some sort out their feelings by talking to friends or family, other cancer survivors/caregivers, or a support group. Talk to a professional about your feelings and concerns. Many caregivers feel overwhelmed and alone. Speaking with a counselor/therapist or oncology social worker may help you cope with some of your feelings and concerns. But even if you prefer not to discuss your burdens with others, you can still sort out your feelings by processing them or writing them down for reflection.

Look for the Positive. Sometimes this means looking for the good even in a bad time or trying to be hopeful instead of thinking the worst. Try to use your energy to focus on wellness and what you can do in the present moment to stay as healthy as possible.

Don't Try to Be Upbeat If You're Not. Many people say they want to have the freedom to give in to their feelings sometimes. As one woman said, "When it gets really bad, I just tell my family I'm having a bad cancer day and go upstairs and crawl into bed."

Find Ways to Help Yourself Relax. Whatever activity helps you unwind, you should take some time to do it. Meditation, guided imagery, and relaxation exercises are just a few ways that have been shown to help others; these may help you relax when you feel worried.

Be as Active as You Can. Getting out of the house and doing something can help you focus on other things besides cancer and the worries it brings. It doesn't have to be high impact, light exercise or gentle yoga and stretching can help too.

Take a Break and Look for Things You Enjoy. You may like hobbies such as woodworking, photography, reading, taking a walk, feeding the birds or crafts. Or find creative outlets such as art, movies, music, or dance. Take some time for yourself regularly. Even if it's just for a few minutes, doing something you enjoy can help you recharge.

Look at What You Can Control. Some people say that putting their lives in order helps. Even setting a daily schedule can give you a sense of control. And while no one can control every thought, some say that they try not to dwell on the fearful ones, but instead do what they can to enjoy the positive parts of life.

Focus On What You Can Provide. It's normal to feel guilty sometimes but understand that no one is a "perfect" caregiver. Believe that you are doing the best you can and making the best decisions you can at any given time.

Seek social support. Try to stay well-connected with family and friends who can offer nonjudgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend or a late-night video chat.

Keep a journal. In addition to deep reflection, writing often helps people organize their thoughts and come up with practical solutions. Writing about your thoughts, feelings and memories can also strengthen your spirit. Use journal prompts to work out a particular feeling or just write in the stream of consciousness style.

Finding Support for Yourself

Although prostate cancer strikes only men, a diagnosis of prostate cancer can have a profound impact on a spouse/loved one/caregiver. The disease and its treatment can have a significant impact on lifestyle, quality of life and emotional well-being for both the patient and caregiver. Some caregivers find it helpful to go to therapy or join a support group. These things can help you cope better and feel less isolated as you make connections with others facing similar challenges.

Find out about caregiving resources in your community. Many communities have classes specifically about the disease your loved one is facing, as well as caregiving services such as transportation, meal delivery or housekeeping. Look for classes and support groups available through caregiver support organizations to help you learn or practice effective problem-solving and coping strategies needed for caregiving while providing validation and encouragement. Other people in support groups understand what you may be going through. A support group can also be a good place to create meaningful friendships. For your health and the health of those around you, it's important to prioritize time to care for your own physical, mental and emotional wellbeing. *For more in-depth information, please reference Section 7. Caregiver Resources & Support Groups.*

Eat Well & Exercise

One way to take care of yourself – physically, mentally, and emotionally – is to exercise regularly. Exercise is the best way to protect your own health and wellbeing during this stressful time in life. Even though it may sometimes be hard to find the time, just 15 or 20 minutes of exercise a day has shown to provide positive health benefits such as helping you to maintain a healthy weight, reduce stress, and improve your overall health. Exercising can be as simple as a walk in your neighborhood, riding your bike, or taking a Zumba class. *For more in-depth information, please reference Section 3. Living with Cancer – Strategy for Fighting & Preventing Cancer with health, nutrition & exercise.* All the same exercise strategies that help fight and prevent prostate cancer can be applied to your personal health and exercise plan to keep you heart healthy and fit!

Mindfulness & Meditation

Recently, more people have recognized mindfulness and mindfulness training as a way to decrease stress and increase psychological functioning with cancer patients. Studies have found that most participants expressed a number of positive

effects after participating in the mindfulness program. These including increased calm, enhanced sleep quality, more energy, less physical pain, and increased well-being. These findings show that through mindfulness, you may be able to enhance your capacity to handle the life stresses that affect the body's ability to heal.

Mindfulness is described as a practice that is about living life as if it matters, to pay attention with kindness and respect to moment-to-moment experiences, no matter how seemingly mundane. Mindfulness can help us to experience life with greater clarity, balance, and gratitude, one moment at a time.

One of the many benefits of practicing mindfulness is that it can promote healing, both physically and emotionally/psychologically. By helping to regulate emotions and allowing a patient to work with the physical pain in the body, mindfulness has helped bring a sense of peace to many people living with cancer.

Here are some tips on how you can practice mindfulness and the benefits therein.

Make Gratitude A Part of Your Routine.

Work on Your Breathing.

Meditation.

Increase Your Awareness.

Watch the World Go By.

Take Control of Your Thoughts.

Take 10 Minutes to Do Nothing.

Meditation is a means of transforming the mind and is described as the written, spoken, or internal dialogue expressing considered thoughts on a subject. It can be done anywhere, for any amount of time, without special equipment or clothing and minimal training. Meditation practices are techniques that encourage and develop concentration, clarity, emotional positivity, and a calm seeing of the true nature of things. By engaging with meditation, you can learn the patterns and habits of your mind, and the practice offers a means to cultivate new, more positive ways of being.

More than 3,000 scientific studies have been conducted on the benefits of meditation, and include positive outcomes for the treatment of depression, anxiety, lack of concentration, high blood pressure, inflammatory disorders, asthma, PMS, Arthritis, Fibromyalgia and more.

Many doctors encourage patients to incorporate this ancient practice into their lives to promote well-being, positive outlooks and even faster recoveries. Research has shown that eight weeks of mindfulness meditation may elevate serum serotonin levels – a compound in the brain that can affect mood and social behavior, appetite and digestion, sleep, memory and sexual desire and function – resulting in a significant decrease in depression, anxiety and stress as well as decreased acute or chronic pain. With regular work and patience these nourishing experiences can have a transformative effect and can lead to a new understanding of life.



HOW TO PRACTICE MINDFULNESS

- ✓ make gratitude a part of your routine
- ✓ work on your breathing
- ✓ meditation
- ✓ take 10 minutes to do nothing
- ✓ increase your awareness
- ✓ watch the world go by
- ✓ take control of your thoughts

visit the ipcf RESOURCES CENTER

to download more tips on meditation and mindfulness

In 2014, a breakthrough Canadian study conducted by researchers at the University of Calgary, (Alberta) and Alberta Health services concluded that meditation may be a powerful complement to treatment plans aimed at altering the cellular activity of cancer survivors. The study, which was published in the journal *Cancer*, was one of the first to suggest scientifically, that a mind-body connection does exist.

Here are some tips on how you can practice meditation and the benefits therein.

Find Your Space. Set up a meditation space.

Find Time. Choose a time when your mind is calm.

Establish a Routine.

Be Comfortable.

Remember to Breathe.

Detach yourself from every-day worries.

Focus.

Observe.

Meditate.

7. CAREGIVER RESOURCES & SUPPORT GROUPS

Caregiver Resources

Being a caregiver can have its challenges. It can feel lonely after your loved one is given a cancer diagnosis. At first, you may wonder how you'll cope. Caregivers need support to increase the chances of having an effective and healthy caregiving experience. You can find strength in sharing thoughts and feelings with others who understand what you're going through. Many Caregivers find outside support is very beneficial. These groups provide a safe haven where you can share your concerns and learn from others who are going through a similar situation. It can also help with providing an outlet for open communication and emotional support for both patient and caregiver.

Knowledge is power and feeling empowered is the first step to gaining balance in any situation. *The International Prostate Cancer Foundation site, www.fightingprostatecancer.org* offers a complete overview of information about the prostate, prostate cancer, and its treatment, and educational materials. Visit the Education Center or the Resources Center to educate yourself on the prostate cancer journey. Learning about the disease is the first level of support for caregiving.

The next and most important level of support comes from building a network you can reach out to when you are in need of support. However, it can be overwhelming to navigate your way through finding these resources and/or support groups that works for you, and/or your loved one. The next section contains information to help you build a strong network of people who are going through a similar experience as you. *For more in-depth information on practical support and respite care reference section 5. Supporting the Patient and Caregiving Basics.*

Remember, while embarking on this journey be kind to yourself. Sometimes, you may feel you could have done something differently or better. Don't dwell on that; instead, focus on all the positive things you are doing for yourself and your loved one.

Communities & Support Groups

A support group is a gathering of people who share a common health concern or similar issues, whether that's, relationship problems, major life changes or illness, such as prostate cancer, diabetes, heart disease, addiction or long-term caregiving. A support group shouldn't replace your standard medical care, but it can be a valuable resource to help you cope.

Support groups are not the same as group therapy sessions. Group therapy is a formal type of mental health treatment that brings together several people with similar conditions under the guidance of a trained mental health provider.

Support groups may be formed by a lay person with the condition or by someone interested in it, such as a family member. In some cases, support groups may be formed by nonprofit organizations, advocacy organizations, mental health clinics or other organizations.

Support groups also come in a variety of formats, including in person, on the Internet or by telephone. They may be led by professional facilitators — such as a nurse, social worker or psychologist — or by group members.



support groups & talk therapy CAN HELP BOTH PATIENTS & CAREGIVERS

Talk therapy helps patients & caregivers to develop the tools and strategies for coping. Group therapy participants note that after only a few sessions, they felt better. Other benefits known are: gaining empowerment, gaining a sense of control and reducing distress, depression, anxiety and fatigue.

Online Communities There are numerous prostate cancer communities and support groups that you can find online. Facebook, Twitter and Google are just a few ways in which to search for, follow, and participate in these support groups and communities.

Organizations that offer online social networking communities and support groups for prostate cancer often display social media icons. Simply click on those icons to join or follow.

Understanding Support Groups Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same situation.

While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges.

Benefits of Support Groups Members of a support group offer one another emotional comfort and moral support, while being a great source of information and encouragement. They may also offer practical advice and tips to help you cope with your prostate cancer treatment or diagnosis and more. Such as:

- Feeling less lonely, isolated or judged
- Gaining a sense of empowerment and control
- Improving your coping skills and sense of adjustment
- Talking openly and honestly about your feelings
- Reducing distress, depression, anxiety or fatigue
- Developing a clearer understanding of what to expect with your situation
- Getting practical advice or information about treatment options
- Comparing notes about resources, such as doctors and alternative options
- Gain instant camaraderie and support
- A chance to talk about your disease and ask questions
- Help coping with advanced prostate cancer, such as how to share news of your disease with others
- Help dealing with practical problems, such as getting to and from doctor visits
- A supportive environment to recognize milestones in treatment

How to find a Support Group What support group, if any, you ultimately choose may depend largely on what's available in your community, whether you have access to a computer or whether you're able to travel.

Plan to attend a few support group meetings to see how you fit in. If the support group makes you uncomfortable or you don't find it useful, try another one. Remember that even a support group you like can change over time as participants come and go. Periodically evaluate the support group to make sure it continues to meet your needs.

Ask your doctor or other health care provider for assistance. Your doctor, nurse, social worker, chaplain or psychologist may be able to recommend a support group for you.

Search the Internet. Online support groups are available as email lists, newsgroups, chat rooms, blogs and social networking sites, such as Facebook.

Contact local centers. Contact community centers, libraries, churches, mosques, synagogues or temples in your area and ask about support groups.

Check your local listings. Look in your local telephone book or check your newspaper for a listing of support resources.

Ask people you know with the condition. Ask others you know with the same illness or life situation for support group suggestions.

Contact organizations. Contact a state or national organization devoted to your disease, condition or situation.

Be aware that you may be at a different stage of coping or acceptance than are others in the support group. Or they may have a different attitude about their situation. Don't feel obligated to keep attending the group if you don't feel it's a good fit — find another group to try.

Find Community. Some caregivers find it helpful to go to therapy or join a support group. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges.

National Association for Home Care & Hospice
nahc.org or 202-547-7424

QUESTIONS TO ASK BEFORE JOINING A SUPPORT GROUP

Each type of support group has its own advantages and disadvantages. You may find that you prefer a structured, moderated group. Or meeting less formally with a small group of people. Some people may prefer online support groups.

- ✓ Is it geared toward a specific condition?
- ✓ Is the location convenient for regular attendance?
- ✓ What is the meeting schedule?
- ✓ Is there a facilitator or moderator?
- ✓ Is a mental health expert involved with the group?
- ✓ Is it confidential?
- ✓ Does it have established ground rules?
- ✓ What is a usual meeting like?
- ✓ Is it free, and if not, what are the fees?
- ✓ Does it meet your cultural or ethnic needs?

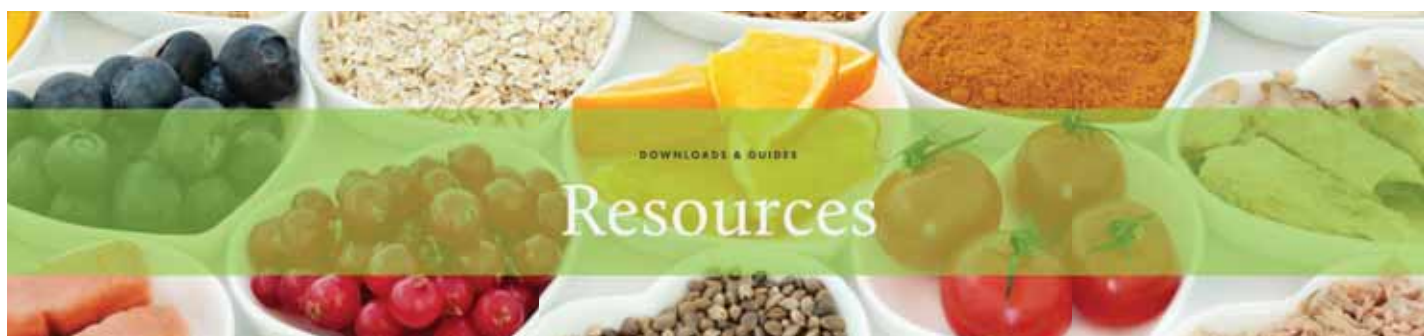
National Family Caregivers Association

301-942-6430 or 800-896-3650

nfcacares.org

Getting the Most Out of a Support Group When you join a support group, you may be nervous about sharing personal issues with people you don't know. At first, you may benefit from simply listening. Over time, though, contributing your own ideas and experiences can help you get more out of a support group.

Remember that support groups aren't a substitute for regular medical care. Let your doctor know that you're participating in a support group. If you don't think a support group is appropriate for you, but you need help coping with your condition or situation, talk to your doctor about counseling or other types of therapy.



Visit the resource center of the IPCF website for prevention tips, support groups, and more!

Visit the downloads link to find all of the infographics, checklists, and strategies in this guide (plus much more) as downloadable pdfs.

www.fightingprostatecancer.org/resources-1