

Caregiving for a
Loved One with
Prostate Cancer

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Each year, nearly 165,000 American men are diagnosed with cancer of the prostate gland. Other than skin cancer, it is the most common cancer affecting men, occurring primarily in men aged 65 or older.

This booklet provides information, guidance and resources for people helping to care for a loved one with prostate cancer. Use this booklet in whatever way works best for you—read it straight through or refer to sections as you need them. Be sure to share the information you find most helpful with your loved one.



The Role of the Caregiver

Caregivers provide important support for a person with cancer. Often, caregivers are family members or friends. They may live with, nearby or far away from the person they support.

Please remember that you should not be alone as you provide support to your loved one. People in your personal network (family, friends, neighbors) will be eager to help, especially if you are specific in your requests. Take some time to think about the people in your life and how they are best suited to help you, and match your request to their strengths—ask a family member who loves to shop to pick up a few things at the store; ask a friend who's a good listener to come over for a chat with you and your loved one.

There are also professional resources available to you, including the oncology social workers at CancerCare, who are specially trained to help people and their caregivers cope with the emotional and practical challenges of cancer. Additional resources are listed at the end of this booklet.

Guidance for Caregivers

The kind of support that a caregiver provides will be different for each person. In general, caregiving support falls into one of three areas: informational, practical and emotional. This booklet provides examples of how caregivers can help in each of these areas.

Informational Support

A man diagnosed with prostate cancer can feel overwhelmed, and may need informational support directly related to his diagnosis and treatment. Here are specific types of support caregivers can provide:

Learn about your loved one's diagnosis and possible treatment options. There is information in this booklet on current treatment approaches for prostate cancer. You will also receive information from your loved one's health care team, and can ask a member of that team what additional resources they recommend.

Understand the potential side effects of the chosen treatment approach. In addition to information on treatment approaches, this booklet lists potential effects of prostate cancer therapy. Some are specific to a certain type of therapy; some are more general side effects that are seen across a number of different therapies. Your loved one's health care team can provide additional information on potential side effects, based on the specific drug or drugs used in the treatment.

Help your loved one communicate with health care professionals. As you help your loved one manage his prostate cancer, it's important to remember that you are both consumers of health care. 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. Here are a few things 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 of 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.
- **Help prepare a list of questions for his next appointment.** This list should include your questions and concerns as well as those of your loved one. Because the doctor may have limited time, create the list in order of importance.
- **Accompany your loved one to medical 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 have forgotten.
- **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.

Practical Support

There are many ways that caregivers can help with practical matters (the activities of daily living), including:

Personal care. Men going through prostate cancer treatment may need help with a number of 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 health care 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.

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

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. This would be a good time to take short-term responsibility for additional chores, if possible.

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

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. There are things you, as a caregiver, can do to help both of you cope:

Listen to your loved one. It's important to listen without judging or "cheerleading." Simply listening to and validating what your loved one is expressing can be one of the most important contributions you make.

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, but don't be afraid to try something new or to make modifications to activities you enjoy.

Support your loved one's treatment decisions. While you may be in a position to share decision making, ultimately it is your loved one who bears the impact of his prostate cancer and its treatment.

Get information about support groups. Joining a support group gives your loved one a chance to talk with others coping with cancer, and learn what they do to manage difficult emotions. Ask a hospital social worker for a referral, or contact CancerCare. CancerCare offers free face-to-face, telephone and online support groups for people affected by cancer.

Continue your support when your loved one's treatment is over. The end of treatment means fewer meetings with the health care team, whose support you have likely relied on. Contact CancerCare or a member of your loved one's health care team for guidance on providing caregiving help during this transitional period.

Remember to Take Care of Yourself

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. Caregiving can be 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 own needs and feelings aside; however, it's important for you to take good care of yourself. Here are some tips to help you do so:

Ask for help. Consider using MyCancerCircle.net™ (<https://mycancercircle.net/>) to organize help from friends and family. MyCancerCircle is a free, private and customizable online tool that enables people facing cancer to organize and coordinate a circle of family members and friends to provide practical and emotional support. MyCancerCircle.net provides caregivers of people facing cancer a simple, effective answer to a question they are asked constantly, "What can we do to help?" You can also use MyCancerCircle.net to look for professional or volunteer resources in your community.

Stay active. Experts recommend at least 150 minutes (2.5 hours) of moderate-intensity aerobic activity per week, preferably spread throughout the week. Aerobic activity includes the use of cardio machines, walking, running, hiking, swimming and dancing.

Pay attention to what you're eating. Keeping a balanced diet is an important part of taking care of yourself. Include fruits and vegetables in your meals. Nuts, yogurt, and peanut butter are easy snacks with lots of protein that will keep your energy level up. Pack snacks if you know you will be with your loved one at the doctor's office or the hospital for an extended period of time.

Get enough sleep. Caregiving can be emotionally and physically draining, and you should try to get enough sleep. 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.

Keep up with your own checkups, screenings and medications.

Your health is very valuable. Stay on top of your own medical appointments, and have a system for remembering to take any medicines you need to stay healthy.

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. Here are some tips to help you cope:

- **Take a break.** Take some time for yourself regularly. Even if it's just for a few minutes, doing something you enjoy (e.g. taking a walk, listening to relaxing music, working on a favorite hobby) can help you recharge.
- **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 or not they are related to caregiving) that you don't have the time or energy to complete.
- **Keep a journal.** 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.
- **Open up to friends and family.** Ask friends or family members if they would be willing to be “on call” in times of stress. You can also plan a regular “check-in” time. Be sure to make time for socializing with friends or family, preferably outside of your home.

- **Talk to a professional about your feelings and concerns.**

Many caregivers feel overwhelmed and alone. Speaking with a counselor or oncology social worker may help you cope with some of your feelings and concerns. CancerCare's oncology social workers are just a phone call away.

- **Join a support group for caregivers.** CancerCare offers free face-to-face, telephone and online support groups for caregivers. These groups provide a safe haven where you can share your concerns and learn from others who are going through a similar situation.

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 your loved one.



Prostate Cancer Treatment Options

When prostate cancer is diagnosed, the tumor most often is localized (confined to the prostate gland). Prostate cancer can also be locally advanced (has spread to nearby tissue) or advanced (has spread to other parts of the body, such as lymph nodes, bones, the liver or the lungs).

Treatment Options for Localized or Locally Advanced Prostate Cancer

The most common treatment approaches for men with localized or locally advanced prostate cancer are:

Active surveillance. An approach for localized prostate cancer only, active surveillance involves the monitoring of the status of the prostate cancer through regular office visits and medical tests, including measuring PSA levels. (PSA—prostate-specific antigen—is a substance produced by the prostate gland which may indicate the presence of cancer.)

Surgery. In a prostatectomy, the prostate and nearby tissue is removed.

Cryotherapy. This approach involves the freezing of the tumor to kill cancer cells.

Radiation therapy. The use of radiation to kill cancer cells in the prostate. Brachytherapy, in which radioactive material is placed inside the body, is one type of radiation therapy that's used to treat prostate cancer.

Hormonal therapy. See the next section, "Treatment Options for Metastatic Prostate Cancer" for information on hormonal therapy. For localized or locally advanced prostate cancer, hormonal therapy may be given before, during and after radiation.

Treatment Options for Metastatic Prostate Cancer

Treatments are available for advanced (metastatic) prostate cancer that can stop cancer growth, control pain and other symptoms, and extend survival.

Hormonal therapy. Also called androgen deprivation therapy, hormonal therapy remains the mainstay for treating metastatic prostate cancer. This type of treatment is aimed at reducing the levels of male hormones (androgens) in the body, or stopping them from affecting prostate cancer cells. The main androgens are testosterone and DHT; they act like a fuel, encouraging prostate cancer to grow. Without androgens, prostate cancer goes into remission, often for many years. (Remission is when all signs and symptoms of cancer disappear.)

Surgery as a form of hormonal therapy. Another way to stop the production of male hormones is an orchiectomy, a surgical procedure in which the testicles are removed. The removal of the testicles causes most prostate cancers to stop growing or to shrink.

Chemotherapy and other treatments. Doctors sometimes recommend chemotherapy as a treatment for hormone-resistant metastatic prostate cancer. One chemotherapy drug is usually given, rather than multiple drugs being given in combination. The drugs typically used are docetaxel (Taxotere) and cabazitaxel (Jevtana).

Combining hormonal therapy with chemotherapy.

Depending on the man's individual circumstances, it is now a standard first-line treatment approach to give the chemotherapy docetaxel in conjunction with hormone therapy.

Other treatment options. A number of other types of drugs have been approved by the Food and Drug Administration (FDA) for metastatic prostate cancer that is no longer responding to hormonal therapy or chemotherapy. These drugs include:

- **Sipuleucel-T (Provenge).** This medication, an immunotherapy, works by using the body's own specialized white blood cells (important parts of the body's immune system), to destroy prostate cancer cells. Sipuleucel-T is used in treating men with asymptomatic or minimally symptomatic castration-resistant disease.
- **Abiraterone (Zytiga).** Abiraterone blocks an enzyme called CYP17, helping to stop cells from producing male hormones. It is used with the corticosteroid prednisone.
- **Enzalutamide (Xtandi).** This drug blocks male hormones from attaching to prostate cancer cells. As a result, enzalutamide can slow the growth of (or destroy) prostate tumors.
- **Radium Ra 223 (Xofigo).** Radium Ra 223 is a drug that contains a small amount of radiation. Approved for the treatment of symptomatic prostate cancer, this drug is injected into the bloodstream and seeks out prostate cancer cells that have spread to the bone.



The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Here are a few things, as a caregiver to a man with prostate cancer, that you should know:

- A member of his medical team can provide guidance as to whether a clinical trial is right for his specific circumstances.
- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before he participates in a clinical trial, he will be fully informed of the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- He can stop taking part in a clinical trial at any time for any reason.

Treatment Side Effects

All cancer treatments can cause side effects. It's important that side effects are reported right away so that your loved one's health care team can help him manage them. Doing so will improve his quality of life and allow him to stick with his treatment plan. Not all men being treated for prostate cancer experience all of these side effects, and men may experience side effects not listed here.

Side Effects of Hormonal Therapy

The side effects of hormonal therapy in the treatment of prostate cancer can include mild anemia, fatigue, changes in cholesterol, mood changes, reduced sexual desire and erectile dysfunction.

Additional potential side effects:

- **Hot flashes.** There are medications that can help if hot flashes occur, such as antidepressants or low doses of female hormones (estrogen or progesterone).
- **Osteoporosis.** Lowered testosterone levels lead to a loss of calcium, which may cause osteoporosis (thinning, brittle bones). Osteoporosis is often treated with bisphosphonates.
- **Weight gain.** Some prostate cancer treatments can cause fluid retention, weight gain and a loss of muscle mass. During treatment, men should stay as active as possible.

Side Effects of Radiation Therapy

Changes to the skin are the most common side effects of radiation therapy. The changes can include dryness, swelling, peeling, redness and blistering. It's especially important to contact the health care team if there is any open skin or painful areas, as this could indicate an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream.

Radiation can also cause mild urinary burning, burning in the rectum, or a change in stool habits. Your loved one's health care team can recommend approaches to alleviate the discomfort of these side effects should they occur.

Side Effects of Chemotherapy

Side effects depend on the type and dose of the chemotherapy and the length of time it is used, and can include:

- Achiness
- Hair loss
- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding
- Changes in memory or thinking
- Peripheral neuropathy (numbness or tingling in hands and feet)

General Side Effects

Some side effects may occur across treatment approaches, including digestive tract symptoms (nausea, vomiting, diarrhea, loss of appetite) and fatigue. The health care team can suggest ways to manage these side effects if they occur.

Managing Pain

Medications such as bisphosphonates can help relieve the pain of prostate cancer that has spread to the bone. Alternatively, radiation therapy is sometimes used to lessen this type of pain. In most cases, stereotactic radiosurgery (SRS) is used. It delivers high-dose, precisely-targeted radiation, which can help preserve healthy tissue.

CancerCare's Free Support Services and Programs

Being a caregiver to a man with prostate cancer can be very difficult, and adjusting to the necessary changes in your life can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how CancerCare can help, call us at 800-813-HOPE (4673) or visit www.cancercare.org.



Frequently Asked Questions

Q: My husband was just diagnosed with prostate cancer. What questions should he and I ask the oncologist about the recommended treatment approach?

A: Here are some questions you should ask; others will likely arise in the course of your discussion.

- What are the goals of treatment?
- How long will treatment last?
- Do you have any written information about this treatment?
- What are the side effects of this treatment?
- Are there any ways to help manage side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any clinical trials we should be aware of?
- What is the best way to let you know when we have questions about treatment?

Q: My brother has prostate cancer. I want to help with caregiving, but I live far away. What can I do?

A: Even from a distance, you can provide ongoing emotional support to your brother and to his primary caregiver. It is sometimes easier for people to talk about difficult topics over the phone than in person, so be willing to have in-depth and serious conversations. You can also help coordinate medical appointments (and send reminders to your brother and his caregiver about those appointments), provide verbal updates to other family members, and share information on how your brother is feeling (if he agrees) in an on-line journal such as CaringBridge.

Q: I've heard that prostate cancer is best managed through a multi-disciplinary approach. What does that mean?

A: The “team” approach—utilizing the skills and experience of a group of health care professionals—is the best approach for treating any type of cancer, including prostate cancer. The medical oncologist is the “captain” of the team, but there other health care professionals who can help your loved one manage his diagnosis and treatment:

- His primary care physician should be kept updated about his cancer treatment and test results.
- Urologists specialize in the diagnosis and treatment of disorders of the urinary system and male reproductive system (including the prostate) and are an important part of the multi-disciplinary team approach in the treatment of men with prostate cancer.
- Radiation oncologists are doctors who treat cancer (including prostate cancer) with radiation therapy.
- Your local pharmacist is a great source of knowledge about the medications your loved one is taking. Have all prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your loved one’s oncologist knows of any other medical conditions he has or any pain he is experiencing so that they can consult with his primary care physician or specialist as needed.

Resources

CancerCare®

800-813-HOPE (800-813-4673)
www.cancercaresupport.org

Prostate Cancer Foundation

800-757-2873
www.pfc.org

The Prostate Net

888-477-6763
www.prostate-online.org

Us TOO International Prostate Cancer Education & Support Network

800-808-7866
www.ustoo.org

American Cancer Society

800-227-2345
www.cancer.org

Cancer.Net

Patient information from
the American Society of
Clinical Oncology
888-651-3038
www.cancer.net

CLINICAL TRIALS WEBSITES

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

National Cancer Institute

800-422-6237
www.cancer.gov

National Coalition for Cancer Survivorship

877-622-7937
www.canceradvocacy.org

Imerman Angels

866-463-7626
www.imermanangels.org

Medicine Assistance Tool

888-477-2669
www.medicineassistancetool.org

CAREGIVER RESOURCES

Caregiver Action Network

800-896-3650,
caregiveraction.org

Family Caregiver Alliance

888-445-8106
www.caregiver.org

My Cancer Circle

www.mycancercircle.net

This booklet is supported by a charitable contribution from Janssen Pharmaceutical Companies of Johnson & Johnson.



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