

# Talking About Prostate Cancer

## A Guide for Talking About Treatment With Your Care Team



This guide can help you take control and have better discussions with your healthcare team after being diagnosed with prostate cancer. This guide provides an overview of prostate cancer and treatment options. You will find helpful questions to ask your doctor, a worksheet to help you set your own goals, and resources for information and support.

### WHAT IS PROSTATE CANCER?

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Prostate cancer is the most common cancer among men. Anyone with a prostate can get prostate cancer. It starts in the prostate, which is a small gland in the body about the size of a walnut. The prostate is located just below the bladder and in front of the rectum. The prostate makes some of the fluid that mixes with sperm to create semen.

Prostate cancer usually grows slowly, and many people do not notice symptoms for years. Prostate cancer symptoms may include:

- **Trouble urinating**
- **Blood in urine or semen**
- **Pain in the lower back, hips, or pelvis**

People with prostates between the ages of 50–69 should talk to their doctor about their prostate cancer screening options. For people with a family history or other factors that increase risk, screening for prostate cancer is especially important. People with potential high risk for prostate cancer should consider screening as early as age 45. For example, having a first-degree relative – like a father or brother – with prostate cancer can increase risk for getting prostate cancer.

**Screening may include:**

A blood test called a prostate-specific antigen, or PSA, test

A check of the rectum and surrounding area using a gloved finger

Different types of medical scans to determine whether the cancer has spread to other parts of the body and plan treatment moving forward

When detected early, prostate cancer may be easier to treat.



To learn more about prostate cancer, visit [www.CancerSupportCommunity.org/Prostate-Cancer](http://www.CancerSupportCommunity.org/Prostate-Cancer).

**TREATMENT FOR PROSTATE CANCER**

Prostate cancer is treated depending on:

**THE STAGE OF  
CANCER YOU HAVE**

**HOW FAST IT  
IS GROWING**

**YOUR AGE AND  
OVERALL HEALTH**

**YOUR PERSONAL GOALS  
AND PREFERENCES**

Some people might need treatment right away, while others may be able to monitor the cancer and wait to treat. Below is a chart that explains the stages of prostate cancer and the treatment options your healthcare team may recommend.

STAGE	DESCRIPTION	TREATMENT OPTIONS
Local, early-stage prostate cancer	Cancer is within the prostate	<p><b>Active surveillance</b> – Regular checkups, blood tests, and scans to watch the cancer</p> <p><b>Surgery</b> – Removal of the prostate (radical prostatectomy)</p> <p><b>Radiation therapy</b> – High-energy rays used to kill cancer cells. This can happen inside or outside of the body.</p>
Local, high- risk prostate cancer	Cancer is growing but has not spread outside the prostate	<p><b>Radiation therapy + hormone therapy (androgen deprivation therapy or ADT)</b> – Reduces the hormones that feed cancer cells and shrinks or kills cancer cells</p> <p><b>Surgery</b> – Removal of the prostate and nearby tissues or lymph nodes</p>
Advanced or metastatic prostate cancer	Cancer has spread to other parts of the body	<p><b>Hormone therapy (ADT)</b> – Reduces the hormones that feed cancer cells</p> <p><b>Chemotherapy</b> – Strong drugs that kill cancer cells</p> <p><b>Immunotherapy</b> – Helps your immune system fight cancer</p> <p><b>Radiopharmaceuticals</b> – Special injected drugs with small amounts of radioactive material used when cancer spreads to other areas</p> <p><b>Targeted therapy</b> – Drugs that work to kill cancer cells if particular gene changes are found</p>

For more information on staging and treatment for prostate cancer, visit [www.CancerSupportCommunity.org/Prostate-Cancer](http://www.CancerSupportCommunity.org/Prostate-Cancer)



## CLINICAL TRIALS

Consider talking to your healthcare team about clinical trials. Clinical trials find new and better ways to treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option.

For more information about clinical trials, visit [www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials).



Below are some of the treatment side effects people with prostate cancer may experience. Think about how often your side effects have affected you since your last doctor's visit. Talk to your healthcare team about how to best manage these side effects.

	Rarely	Sometimes	Often
<b>Fatigue (feeling very tired)</b>			
<b>Urinary problems (trouble urinating, leaking urine, going more often)</b>			
<b>Bowel movements (diarrhea, constipation, urgency, discomfort)</b>			
<b>Sexual health problems (trouble getting or keeping an erection, lower sex drive)</b>			
<b>Hot flashes (with ADT)</b>			
<b>Weight loss or gain, loss of muscles</b>			
<b>Mood changes (feeling worried, anxious, overwhelmed, depressed)</b>			
<b>Other side effects not listed here:</b>			

Visit [www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects](http://www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects) for more information on managing treatment side effects.

## PALLIATIVE CARE

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Palliative care is a type of support that helps you feel better during or after cancer treatment. It focuses on relieving symptoms, like pain or fatigue. A palliative care specialist can help you manage any side effects and feel more comfortable.

Palliative care is different from hospice care. It is available at any point during your cancer experience. It can be available as early as the time of diagnosis. Palliative care is available for people with any stage of cancer. You can receive it at the same time as your cancer treatment. The goal of palliative care is to help you live as well as possible throughout your cancer experience.



## THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

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When talking to your doctor about your treatment options, ask about the goals of the treatment and how each might impact you. If you choose not to receive treatment, think about your goals for the supportive care that you want to receive.

**Possible personal goals may be to:**

- **Live as long and as well as possible**
- **Become an advocate**
- **Participate in research**
- **Attend a special event/milestone**

Let each member of your healthcare team know about your treatment and personal goals. Remember that your goals may change over time, and that is OK.

Your treatment is about more than just attacking the cancer cells – it is about living the life that matters most to you. Thinking about your personal goals can help your care team recommend options that fit your values, lifestyle, and priorities.



## SETTING YOUR PERSONAL GOALS FOR TREATMENT

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Here are some questions for you to consider and discuss with your doctor. You may want to write down your answers and bring them to your next appointment.

### Physical, Emotional, & Sexual Health and Well-Being

What is most important for you to be able to do and feel?

What do you want to be able to do physically during or after treatment?

Which symptoms or side effects do you want to avoid or manage?

How important is it to maintain your sexual health and intimacy?

What does feeling emotionally well look like for you?

### Family and Social Relationships

What is happening in the lives of others that are important to you?

Are there people you would like to spend more time with or support?

Are there upcoming family milestones or events you want to be present for?

How can you keep your relationships strong during treatment?

Do you have a reliable caregiver or support person who can assist you during your treatment?

How can you best support your caregiver(s) while they are supporting you?



### **Work/School/Home**

Do you want to keep working or attending school? Why is that important to you?

What changes could help you balance treatment with your responsibilities?

What kind of help do you need at home or with daily tasks?

### **Social Support & Community Involvement**

Are you getting the support you need from friends, family, or community?

What would good support look like for you right now?

Is staying involved in your community, advocacy, or support groups important?

### **Personal and Spiritual Growth**

What spiritual and wellness practices are important to you? Are you taking care of yourself spiritually and emotionally?

Are there spiritual practices or beliefs that bring you comfort?

What helps you feel connected to something bigger than yourself?

What personal or emotional goals do you want to focus on?

### **Other**

What else is important to you?

## **WORKING WITH YOUR CARE TEAM**

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Cancer treatment is complicated and continues to change as new discoveries are made. That is why it is important to have a healthcare team you can trust to give you the best care possible. The team can include doctors, nurses, and other healthcare professionals who work together. This is often referred to as “multidisciplinary care.” You may also work with a palliative care specialist. They focus on helping you feel better by easing pain and other symptoms.

It is important that you feel comfortable to talk openly about your cancer and symptoms with your care team. You may have options for your treatment, so let them know what matters to you. Ask questions, share your worries, and speak up if something does not feel right. You should feel heard and supported during your cancer experience.

## QUESTIONS TO ASK YOUR CANCER CARE TEAM

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What stage is the cancer?

Where is the cancer located?

Has the cancer spread? Is the cancer considered “advanced”?

Does the cancer have a high chance of returning?

Do I need any other tests or scans to treat my cancer?

What are my treatment options?

What are the benefits and risks of each treatment option that is available for me? What side effects should I watch out for?

Are there other treatments options that work just as well but would cost me less?

Are there clinical trials that could help me?

Will my ability to urinate or have sex change during treatment?

The symptoms and side effects that are bothering me the most are: [See page 4.]

- These side effects are affecting my daily life in these ways:
- What can we do to manage these side effects?

My top goals for treatment are: [See page 6.]

Can I keep working during treatment?

What can I do to stay active and feel better?

Is there a support group or social worker I can talk to about my experiences?

Who can I talk to if I am feeling overwhelmed?



## FINANCIAL SUPPORT

Even with a healthcare plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

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Talk with your healthcare team and pharmacist about the cost of your treatment.

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Ask your doctor to refer you to an oncology social worker, financial counselor, or nonprofit organization for help managing financial issues and costs. You can also contact the Cancer Support Community's Helpline to speak with a financial navigator, who can help you understand your options and connect you with financial resources.

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Reach out to your healthcare plan or insurance to find out what resources they have that could help you.

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Ask about pharmaceutical assistance programs and what the qualification requirements are.

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If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.



To learn more about ways to manage the cost of treatment, visit:  
[www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment](http://www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment).

## GETTING SUPPORT

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Think about people in your life who can help (your spouse or partner, family, friends, faith community, support group, or co-workers).



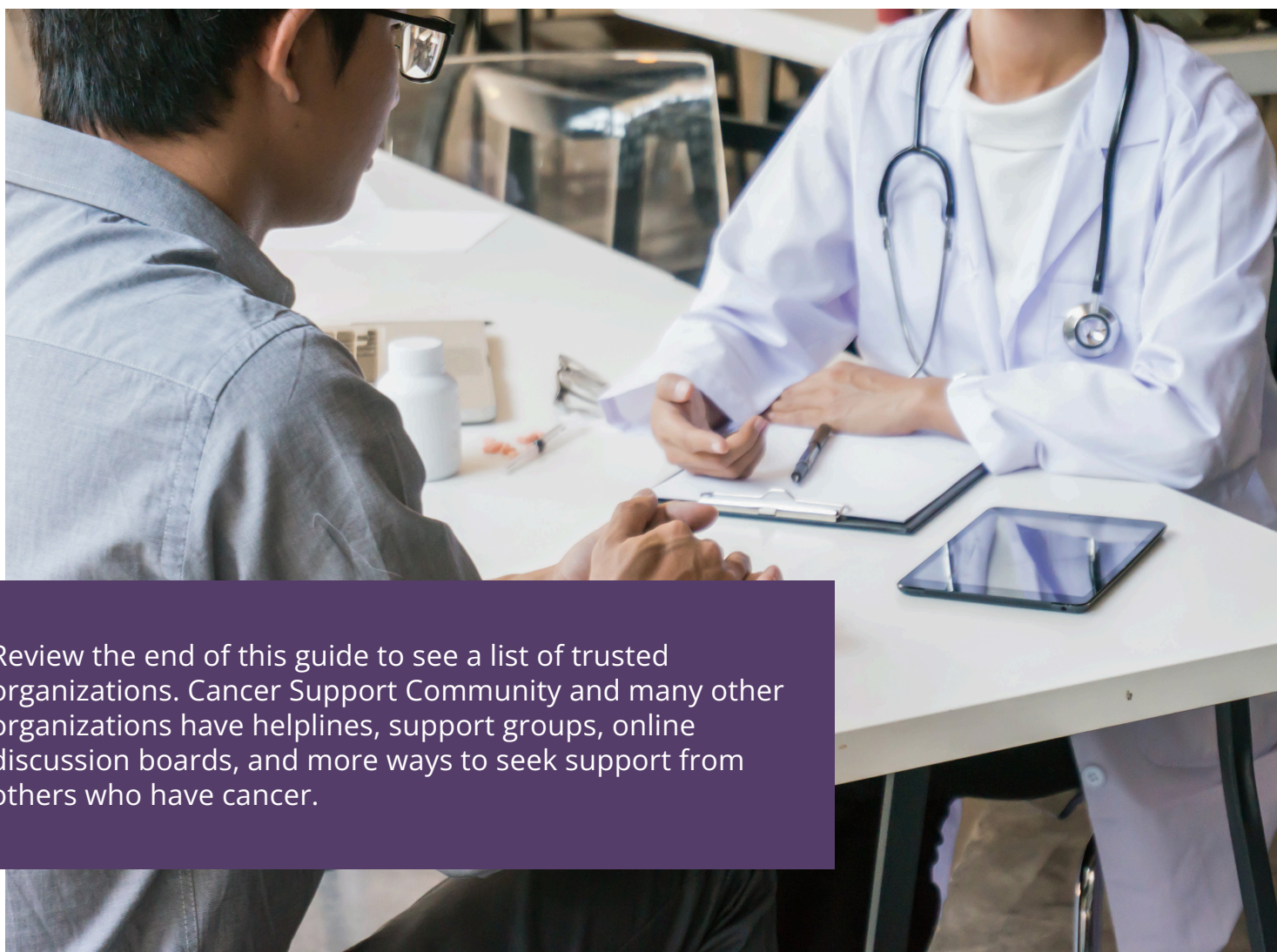
Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider visiting [www.MyLifeLine.org](http://www.MyLifeLine.org) to help you stay organized and let friends know what you need.



If you search for information online, make sure that you are using trusted websites.



Ask your healthcare team about resources for social, emotional, and practical support. You can also ask for a mentor or ask to connect with another person with prostate cancer.



Review the end of this guide to see a list of trusted organizations. Cancer Support Community and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.



## PROSTATE CANCER RESOURCES

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### **Cancer Support Community**

[www.CancerSupportCommunity.org/Prostate-Cancer](http://www.CancerSupportCommunity.org/Prostate-Cancer)

### **Cancer Support Community**

[www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment](http://www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment)

### **MyLifeLine**

[www.MyLifeLine.org](http://www.MyLifeLine.org)

### **Cancer Support Community**

[www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects](http://www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects)

### **Cancer Support Community**

[www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials)

### **American Cancer Society – Prostate Cancer**

[www.cancer.org/cancer/prostate-cancer.html](http://www.cancer.org/cancer/prostate-cancer.html)

### **National Cancer Institute – Prostate Cancer**

[www.cancer.gov/types/prostate](http://www.cancer.gov/types/prostate)

### **ClinicalTrials.gov (for broader clinical trial listings)**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### **Us TOO / ZERO Prostate Cancer**

[www.zerocancer.org](http://www.zerocancer.org)

## Cancer Support Community Resources

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**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more  
**[www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)**.

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at **[www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org)**

**MyLifeLine®** — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **[www.MyLifeLine.org](http://www.MyLifeLine.org)**.

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **[www.CancerSupportCommunity.org/Become-Advocate](http://www.CancerSupportCommunity.org/Become-Advocate)**.

This publication is available to download and print yourself at **[www.CancerSupportCommunity.org/Prostate-Cancer](http://www.CancerSupportCommunity.org/Prostate-Cancer)**.

For print copies of this publication or other information about coping with cancer, visit **[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org)**.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other healthcare professionals to answer questions and learn more.

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