



# Empower Yourself With Knowledge

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Principles for managing advanced prostate cancer

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**Us TOO**<sup>®</sup>  
PROSTATE CANCER  
EDUCATION & SUPPORT



“Where the  
MIND GOES...  
the body  
FOLLOWS.”

—Bill Blair, founder of Mets Mavericks, an  
Us TOO support group formed to help men  
with advanced prostate cancer

## Learning to cope through knowledge and hope

This guide is designed to help you and your loved ones stay informed about advanced prostate cancer, managing the disease, and taking steps to keep healthy. In it, you can find the **7 principles of empowerment**.

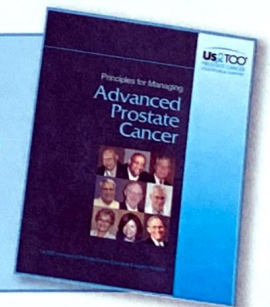
This information can help you:

- Work closely with your doctor and healthcare team
- Learn about possible treatments
- Take an active role in making smart decisions about your treatment

The information in this guide is for men with **advanced prostate cancer** such as **castrate-resistant prostate cancer**. *Castrate-resistant prostate cancer* means that the cancer is resistant to medical or surgical treatments that lower testosterone. This type of cancer may still respond to hormonal treatments.

Remember that you're not alone. When you need support, reach out to family and friends and to other men with advanced prostate cancer. Connecting with someone who has been in your shoes, or is on a journey similar to the one you are on now, can help answer your questions and help you cope.

Us TOO International Prostate Cancer Education & Support Network has a booklet called the *Principles for Managing Advanced Prostate Cancer* and a kit with more detailed information on the **7 principles of empowerment**.



To access the support materials, go to [ustoo.org](http://ustoo.org) and under the Helpful Resources tab, click on "Advanced disease or recurrence." Or call (800) 80-Us TOO (800-808-7866) to request the booklet and the kit.



# 1 Chart Your Disease Data

To get the most from your care, it may help to create a system to track your medical information. You can use hard copy or an electronic system.

Find something that will make it easy for you to update your records often.

Share the information you track with your healthcare team so you can work together to manage your cancer and treatments.

## Use your system to help track your:

- Medical history: When were you diagnosed? Do you have any other medical issues?
- Healthcare providers' contact information
- Medicines: name, dosage, schedule, treatment goals, side effects
- Medical procedures and test results
- Side effects, eating plan, exercise routine

## When you make a tracking system, keep the following tips in mind:

- **Pay attention to details**
  - Take notes and record dates of when something important happens
- **Stay organized**
  - Put your documents in a folder where you can easily reach them
- **Hold on to your own records and keep them backed up**
  - Make copies of your most important documents

If you can't make a tracking system or update your records on your own, ask a family member or friend to help.

This is an example of a tracking chart from the *Principles for Managing Advanced Prostate Cancer* booklet.



SUBSTANCE	DOSAGE	START DATE	STOP DATE	BENEFIT/DESIRED EFFECT	SIDE EFFECTS

# 2 Assessing Your Disease State

Your healthcare team will use tests to monitor your cancer. Your healthcare team can also do tests to see where the cancer cells are in the body.

Knowing this information may help you and your healthcare team make treatment decisions that are right for you. These medical tests and scans may include:

- Prostate-specific antigen (PSA) screening
- Magnetic resonance imaging (MRI)
- Computed tomography (CT) scans – either pelvic or abdominal
- Other tests, such as positron-emission tomography (PET) or circulating tumor cells (CTC) test
- Bone scans
- Physical exam



When you have any of these tests, talk with your doctor about the results and what they mean. Also, ask for copies of the results or of any test images. You can keep your results in your tracking system. Some doctors' offices also store test results in electronic health records. Ask your doctor if and how you can access these records for your results.

Once you and your healthcare team assess your cancer, together you can choose a treatment option that may help slow your cancer growth.

Don't forget to also keep track of how you feel. If you have unusual or new symptoms, let your healthcare team know.



## 3 Identify Your Treatment Options

Your doctor will determine if your advanced prostate cancer has progressed and will talk with you about treatment options.

**Here are some tips that may help you talk about your treatment options:**



Do research on your disease and talk with other men who have advanced prostate cancer about their treatments.

- If you're interested in a specific treatment, it may help to seek out a doctor who has experience with that treatment



Make a list of questions and prioritize them for the healthcare team.

- Being prepared and taking notes can help you remember important points



Bring a family member or close friend to your doctor appointments.

- Another person can take notes and help catch details that you may miss

Remember that it's also okay to get a second opinion. Hearing another's point of view may help you see things in a different way. Another doctor may also know more about treatment options that you may want to pursue, or he or she may be a better fit for you.

**Think about asking these questions during your office visit:**



- What treatment do you recommend and why?
- How will you know if my treatment is working?
- What resources are available to me to help me learn more about my treatment?

## 4 Develop and Reassess Your Treatment Plan

Once you find a doctor you trust, you can talk about treatment options and make a plan that's right for you. You can be on more than 1 type of treatment at a time. There have been many recent advances in advanced prostate cancer treatment approved by the Food and Drug Administration (FDA). New treatments are allowing men to live longer. That's why it's important for you and your doctor to reassess your plan over time.

Treatments usually fall into the following categories:

- **Hormone treatments**

- These treatments can affect male hormones (called *androgens*) or testosterone, by lowering the amount in the body
- Hormone treatments can also affect the androgen receptor and can interfere with the interaction of the androgens with the receptors
- Some of these medicines can stop hormones from telling the cancer cells to grow
- Your doctor may suggest new hormone treatment options that work differently from older hormone treatments

- **Radiation**

- High-energy waves that target specific areas in the body to kill cancer cells

- **Immunotherapy**

- Medicines that help the body's immune system attack cancer cells

- **Chemotherapy**

- Medicines that kill cancer cells or stop cancer cells from growing

- **Clinical trial**

- A research study using a treatment option that you and your healthcare team can talk about
- May help researchers find new treatments for men with advanced prostate cancer



**If you're worried about paying for your cancer treatment, there are resources that can help. Ask your doctor about financial assistance programs you can access.**



## 5 Anticipate Side Effects and Know How to Manage Them

Many men may have side effects as a result of their prostate cancer and its treatments. Each treatment may have different side effects. But if you know what to expect, it may be easier to deal with the changes.

**Here is some information that may help you manage these side effects. Please talk with your doctor about:**

- **Maintaining bone health**
  - Advanced prostate cancer and some of its treatments can weaken your bones. Talk with your doctor about medicines that you can take to help keep your bones strong
- **Minimizing pain**
  - Keep track of your pain and how severe it is. Be sure to talk with your doctor if you have any pain. He or she may be able to help you find relief
- **Managing incontinence**
  - You may have dealt with incontinence when you first had surgery or radiation, or you may still be dealing with it now. Your doctor can suggest options to help you
- **Maintaining intimacy**
  - Remain open with your partner about how you're feeling. Remember that sex is not the only way to be intimate. Kissing, hugging, and tender touching are all ways to create physical closeness
- **Maintaining overall health**
  - Getting enough exercise, following a healthy diet, managing stress, and staying hydrated may help you manage some of the common side effects of advanced prostate cancer and its treatments. Talk with your doctor before you start a new eating or exercise plan

It may also help to talk with other men who have advanced prostate cancer. To find a support group, go to [ustoo.org](http://ustoo.org) and under the Chapters & Support Groups tab, click on "Find a Support Group Chapter Near You."

## 6 Recognize the Eventual Need for an End-of-Life Plan

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

One thing to consider when making a plan is the care that you want at different stages of your disease and treatment. At some point, you may need to think about **palliative** and **hospice care**.

**Palliative care** is support and medical care given by your healthcare team that can help you deal with pain, stress, and other symptoms while you are still on treatment. **Hospice care** is palliative care that is intended for those with a life expectancy of 6 months or less.

It's also important to prepare your legal documents. This will ensure that your wishes are kept and your family has what they need.

**Be sure to set up:**

- **Power of attorney** • **Living will** • **Conventional will**

Talking with your family and filling out legal documents may help lessen the worry about your care. It may also help ensure that your family and healthcare team are prepared to help you.

When you are thinking about your end-of-life plan, it may help to talk with someone other than your family and friends. A social worker, psychologist, counselor, or someone else with advanced prostate cancer may be able to help you. You can also find someone to talk with by joining a support group.





## 7 Empower Yourself Daily Through Diet, Exercise, Spirituality, and Humor

When you have advanced prostate cancer, many changes may occur. While your treatments or end-of-life plan may seem to take center stage, it's important to think about how you can empower yourself on a day-to-day basis.

Be sure to take care of your physical, emotional, and spiritual self during your treatment.

Here are some tips to keep in mind:



### Diet

- The foods you eat may help keep up your energy levels. Work with a nutritionist or your doctor to come up with an eating plan that works for you



### Exercise

- Staying active may help maintain bone strength, build muscle, and keep your mood positive. Find an activity that you enjoy, and talk with your doctor to decide how much you can do



### Laughter

- Laughter may help reduce stress and increase endorphins, or “feel good” hormones



### Spirituality

- Meditating, counseling others, or prayer may help calm the mind and relax the body. Find something that brings you peace and helps you connect with yourself and what is important to you

All of these may help build a better connection between mind and body.



**Remember to talk with your doctor before making any changes to your diet plan or exercise routine. Also talk with your healthcare team if you want to try other techniques to relieve stress and pain.**

This guide can help empower you to better manage your treatment for advanced prostate cancer.

You can review the **7 principles of empowerment** any time you need quick tips on how you can manage your disease and stay healthy.

#### 1 Chart Your Disease Data:

Update your records often.

#### 2 Assess Your Disease State:

Know what your test results mean.

#### 3 Identify Your Treatment Options:

Stay informed about available treatments.

#### 4 Develop and Reassess Your Treatment Plan:

Review your treatment plan over time.

#### 5 Anticipate Side Effects and Know How to Manage Them:

Don't wait to ask for help in finding relief.

#### 6 Recognize the Eventual Need for an End-of-Life Plan:

Share your wishes with your family and healthcare team.

#### 7 Empower Yourself Daily Through Diet, Exercise, Spirituality, and Humor:

Do things that make you happy.

Remember that knowledge is hope. Learn as much as you can about your disease, treatment options, possible side effects, and how to maintain a healthy lifestyle. Work together with your family and healthcare team to make the best of your care and to find comfort every day. Connect with someone who is in a situation similar to yours.

To learn more, read the full *Principles for Managing Advanced Prostate Cancer* booklet. To access it, go to [ustoo.org](http://ustoo.org), and under the Helpful Resources tab, click on “Advanced disease or recurrence,” or call (800) 80-Us TOO (800-808-7866) to request the booklet.

The information in this guide is not meant to replace the advice of your doctor. Talk with your doctor if you have any questions about your advanced prostate cancer or treatment.



## Resources

Use these resources to learn more about advanced prostate cancer, managing the disease, and finding support.

- Us TOO International Prostate Cancer Education and Support Network  
[ustoo.com/Advanced\\_Disease.asp](http://ustoo.com/Advanced_Disease.asp)
- Us TOO Inspire Online Discussion Community  
[inspire.com/groups/us-too-prostate-cancer/topics/recurrence-advanced-disease](http://inspire.com/groups/us-too-prostate-cancer/topics/recurrence-advanced-disease)
- Prostate Conditions Education Council  
[prostateconditions.org/prostate-conditions/prostate-cancer/advanced-disease](http://prostateconditions.org/prostate-conditions/prostate-cancer/advanced-disease)
- Malecare Advanced Prostate Cancer Program  
[advancedprostatecancer.net](http://advancedprostatecancer.net)
- National Cancer Institute  
[cancer.gov/cancertopics/coping/advancedcancer](http://cancer.gov/cancertopics/coping/advancedcancer)
- Advanced Cancer Care Planning from The American Society of Clinical Oncology  
[cancer.net/coping/advanced-cancer-care-planning](http://cancer.net/coping/advanced-cancer-care-planning)

The medical information and procedures contained in this guide are not intended as medical advice, nor are they intended as a substitute for consulting with a physician or healthcare provider. All matters pertaining to your health should be supervised by a healthcare professional. This material is intended to be used only for educational purposes. It is not a substitute for informed medical advice from a physician.

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