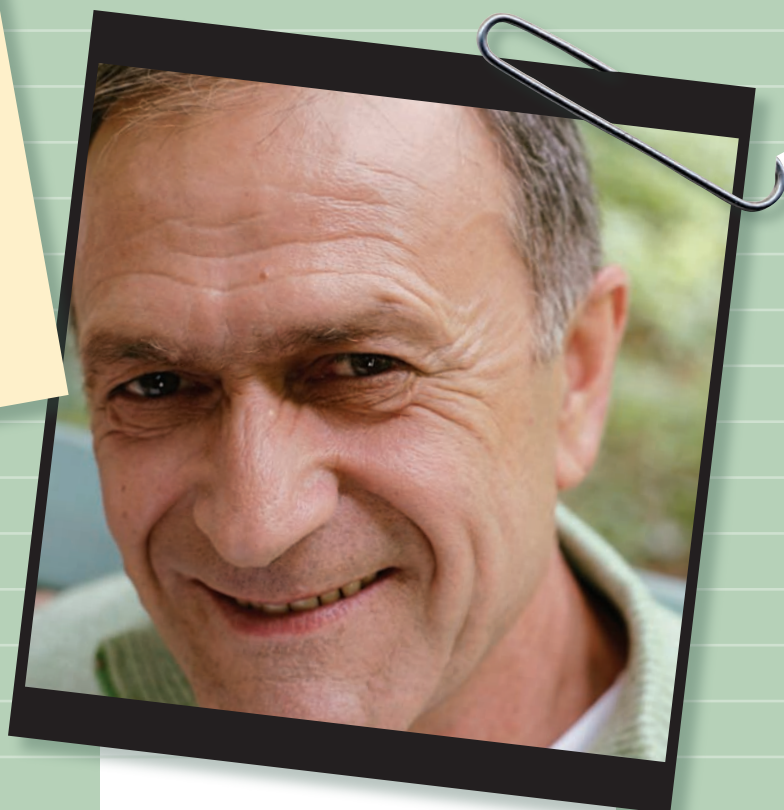


For Prostate Cancer Recurrence, Rising PSA, and Advanced Disease

The Prostate  
Cancer  
Playbook



Strategies for  
Building Teams,  
Optimizing Treatment,  
and Living Well

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

Someone to talk to...  
who understands!

# Welcome!

Knowledge  
is Power

*"I was devastated that I had metastatic prostate cancer until my wife made me realize that we had to stop being passive and take charge. We read everything, talked to everyone and explored the Internet. That led us to change doctors, to start having hope, and to act more rationally."*

*- Tom*

Are you or someone you love facing a recurrence of prostate cancer, a rising PSA, or cancer that is no longer responding to treatment? Maybe the cancer has advanced, or even spread. Whether you are the patient, a spouse, a companion or a family member, you may be experiencing some or all of the following thoughts and concerns:

- **Decisions about getting second opinions, seeing a new specialist, or trying different treatment options are weighing heavily upon you.**
- **Thoughts about an uncertain future are clouding everyday thoughts and feelings.**
- **Fears about pain associated with the cancer are surfacing.**
- **Discussions with loved ones, or perhaps the lack of discussion, are upsetting you.**

If these thoughts and concerns sound familiar, then this booklet may serve as a valuable guide.

## *The Us TOO Prostate Cancer Playbook*

Us TOO International has over 16 years of experience serving men with prostate cancer and their loved ones. We have gained unique insight into how patients with prostate cancer effectively manage their disease while maintaining a higher quality of life than they had thought possible. These insights, experiences and important medical information are available here to you.

While The Prostate Cancer Playbook speaks to the patient, it is a valuable resource for the entire family and will educate and empower you and your loved ones to:

- **Become more effective and confident in your decision making**
- **Better cope with the continuing impact of cancer on your lives**
- **Provide strength to one another**
- **Discover new meaning in life as you deal with this disease**

*Let's get started!*

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*Us TOO International is a grassroots organization that was started by prostate cancer survivors in order to communicate timely and reliable information to men with prostate cancer, their spouses/partners and families, enabling them to make informed choices regarding the detection and treatment of prostate cancer.*

# The Home Team Advantage: Se

In team sports, the home team has a significant advantage over the visiting team because of the enthusiastic fans that fill the home stadium and passionately root for the team, energizing them to get the competitive juices flowing, go the extra yard, and score winning points.

In prostate cancer, you also have a home team advantage – the encouragement and assistance of supportive family and friends!

While your physicians may change over time, your family and friends will remain a constant in your life, making their support and involvement critically important.

With this powerful advantage available to you, have you asked your loved ones:

- **To join your home team (e.g., a wife, partner, adult child, family member, best friend or several of these individuals)?**
- **To take a more active role in understanding your disease?**
- **To partner with you to better manage your disease for the best possible outcome?**

You Are  
the Team  
Captain

*Every team needs a leader.*

*Since this is your life, you are in charge. When selecting your teams, pick the most knowledgeable, capable and supportive individuals in order to create teams uniquely suited to treat and care for you.*

*Get started today – this cannot wait. Remember, you do not need to go through this alone.*

# Selecting Your Team

## A Family United

Doris and I had been married nearly 40 years when I was diagnosed with prostate cancer in 2000. I had been participating in a study on aging at John Hopkins for 15 years when researchers detected something disconcerting – prostate cancer.



Together, we learned of recommended treatment options. Being more computer savvy, Doris did a lot of the research and brought that knowledge to every appointment with me. In the midst of making a decision, a colleague of mine suggested I meet with an exceptional surgeon at Walter Reed Army Medical Center. He spent

four hours with us discussing the treatment options, introducing the staff, and welcoming me like a brother. Once again, Doris and I made a decision together.

When we told our two children about my diagnosis, we tried to be very upfront about the cancer and treatment options. As I prepared myself for surgery, our family home team came together effortlessly, each providing support in a different way. Looking back, I was blessed to be surrounded by the love of my family.

— Kenneth

*Important Facts  
Every African  
American Should  
Know About  
Prostate Cancer*

- African American men have the highest rate of prostate cancer in the world. In fact, the incidence rate for African American men is 60% higher than in white males.
- The mortality (death) rate for African Americans with prostate cancer is double that of white males.
- Prostate cancer is the fourth leading cause of death among African American men over the age of 45.

*Us TOO strongly recommends that all African American men see their doctor for a digital rectal exam (DRE) and prostate-specific antigen (PSA) blood test annually beginning at the age of 40, and carefully track their PSA test score each year.*

*If you know someone who could be affected, share this important information with him.*

# The Home Team Advantage: Getting

Informative  
Web Sites on  
the Internet

"Finding information on the Internet is like drinking from a fire hose."

– Don Lynam, Vice Chair of the Us TOO Board of Directors

Below are a few recommended sites to help you get started:

- Us TOO International  
([www.ustoo.org](http://www.ustoo.org))
- Prostate Cancer Research Institute  
([www.prostate-cancer.org](http://www.prostate-cancer.org))
- Prostate Forum with Dr. Charles "Snuffy" Myers  
([www.prostateforum.com](http://www.prostateforum.com))

## Become Informed

- Speak with other prostate cancer patients
- Ask your librarian for books and articles
- Join an Us TOO Chapter Support Group, or local cancer support group
- Consult online resources
- Read Us TOO's publication *What Now?* for more in-depth information. Request a copy by calling 1-800-808-7866, or download at [http://www.ustoo.org/PDFs/160295\\_PSA\\_Brochure.pdf](http://www.ustoo.org/PDFs/160295_PSA_Brochure.pdf)

## Explore All Disease Treatment and Management Options

- Learn about recurrent or advanced disease, new treatment options, pain medications, clinical study possibilities, health and fitness regimens, stress management techniques and more

## Work Together with Your Medical Team

- Attend medical appointments with a member of your home team
- Ask questions (physician questions are provided in the Worksheets section) and have your team member write down the answers
- Bring a tape recorder to record your discussion with your physician, ensuring that all details are captured and providing the option to replay the discussion at a later date or time
- Talk with your doctor(s) about concerns you may have
- Become a self-advocate. Speak up and request information on the most appropriate treatment options available

# Getting Started

## Find the Best Available Treatment Plan

- Review your findings with your home team and share your thoughts and concerns
- Determine the best course of treatment after careful consultation with your medical team and open discussion with your home team

## Team Work

- Acknowledge and speak openly with the members of your home team during this process, recognizing the contributions, support and love they provide (e.g., a thoughtful card, a bouquet of flowers, tickets to a game, dinner at a favorite restaurant, or maybe a hug)
- Work together with your home team to share disease and treatment news with family and friends
- Communicate your feelings with one another. Your fears and hopes are equally important to assess as the clinical information (see Conversation Starters)

Conversation Starters:  
Unmet Dreams?

Team members who communicate report feeling better and less distressed.

Do you need help getting started? Try one of the following:

- Are you satisfied with your treatment and care?
- How do you feel about my participation in your health care?
- What are your greatest needs as a primary caregiver?
- What are our unmet dreams?



# Your Medical Dream Team: Asse

## Your Key Players

- **UROLOGIST:** *A surgeon who specializes in diseases of the urinary and sex organs*
- **RADIATION ONCOLOGIST:** *A doctor who specializes in using radiation to treat cancer*
- **MEDICAL ONCOLOGIST:** *A doctor who is trained in the diagnosis and treatment of cancer and specializes in the use of chemotherapy and other drugs to treat cancer*

Typically, your medical team will include an Urologist/Surgeon, a Radiation Oncologist and a Medical Oncologist.

Look for the very best and assess their experience based on certain qualifications, such as:

- **Level of training/education**
- **Number of years practicing**
- **Amount of experience with your particular diagnosis and circumstances**

Note: You want your physicians to be team players – they need to be able to work with you, your family and your other physicians.

## Equip Yourself with Information

Now that you have a new diagnosis, you and your loved ones may be consumed with many pressing questions:

- **Why isn't the treatment working?**
- **What does this diagnosis mean?**
- **What options do I have?**
- **Where can I turn for support?**
- **Why is this happening?**

Be persistent in your search for answers. Turn to your home team, medical team, other patients and survivors for information. The best offense is a good defense, and a good defense is to be informed.



# Building Your Medical Team

## Creating a Supportive Home Team

When Maureen and I were in our early 50s, I was diagnosed with prostate cancer. We were completely shocked. At that time, gathering information was more challenging than today. After reading Dr. Bernie Segal's *Love, Medicine and Miracles*, we decided we not only wanted treatment choices that cared for the body, but also for the mind and spirit. We began a daily practice of reading, sharing tea, and meditating together. We wanted doctors who approached us like a team and embraced our holistic approach. We also created a supportive home team environment with our friends, surrounding ourselves with other couples like us, ones who cherished and honored each other. - Jim



# Your Medical Dream Team: Devel

It is time to develop a game plan:

1. **Get a full explanation of your diagnosis and treatment options from your Urologist, and keep asking questions until you clearly understand.**
2. **Seek second opinions from other specialists (i.e. a Radiation Oncologist and Medical Oncologist) by asking your Urologist and other patients for referrals.**
3. **Keep copies of all of your medical records. When requesting copies, be insistent, if necessary. When visiting a new doctor, insist that the referring office transfer your medical records.**
4. **Prepare a list of questions in advance of each medical appointment (see suggested questions in Worksheets section).**
5. **Some treatment scenarios may begin to emerge:**
  - **If both specialists agree that surgery is best, it probably is best.**
  - **If both specialists agree that radiation is best, it probably is best.**

## A Second Opinion

*Getting a second opinion is common practice. If your doctor does not support this decision, then it may be time to find a doctor who does. A second opinion may provide more information on a treatment that you are considering (i.e. risks vs. benefits, lifestyle changes, etc.) or one that you have not yet considered. In some cases, your insurance company may require a second opinion.*

In some cases, your physicians may have differing opinions. If this happens, it is important that you carefully consider what is best for you and your family or get a second or even third opinion.

# oping a Game Plan

## Knowing the Score – Tracking Your Changing PSA Values

At all stages of prostate cancer, regular monitoring of PSA levels is critically important. However, with recurrent or advanced prostate cancer, fluctuations and rate of change of your PSA value (called PSA velocity) can reveal certain patterns or cycles, providing helpful information to your medical team and you for making treatment decisions or changes. This can be accomplished by regularly tracking your:

- **PSA level**
- **Testosterone**
- **Dihydrotestosterone (DHT)**
- **Timing of treatment or medication changes**

A tracking worksheet is available, go to page 34-35.

Important: Note your actual numbers from your doctor, not vague references like “it falls within an acceptable range.”

Monitoring changes to your Gleason score also is important to determine the extent of disease and the best treatment strategy.

To learn more about PSA values, the Gleason system and score, visit [www.ustoo.org](http://www.ustoo.org) and search for “PSA value” and/or “Gleason score.”

## *Examining Your Strategies: Assessment*

To improve a team's winning record, players and tactics are constantly re-evaluated and changed. Similarly, prostate cancer is an ever-evolving challenge, particularly when you experience recurrence, advanced disease or cancer that is not responding to treatment.

Now is the time to review all of your options, taking into consideration past treatments as well as your treatment objectives.

However, first you and your medical team need to know:

- **Is the cancer localized?**
- **Has the cancer spread?**
- **Are the bones involved?**
- **Does an elevated PSA value really mean a cancer recurrence or is it simply a “bump,” common after brachytherapy?**
- **What are my PSA and other tests telling us?**

To answer these important questions, your medical team and you will need to select the right assessment tests, which will provide valuable information, allowing you and your medical team to make informed treatment decisions that are most appropriate for you.

# ining Your Strategies

Assessment tools that may be used include:

- **Bone Scan**
- **Computed Tomography (CT) Scan**
- **Magnetic Resonance Imaging (MRI)**
- **Magnetic Resonance Spectroscopy**
- **Positron Emission Tomography (PET) Scan**
- **ProstaScint®**
- **ProstaScint® Fusion Imaging**
- **Combindex (only available outside of the U.S.)**

A lymph node biopsy also may be done to find out if your cancer has spread into nearby lymph nodes. If it has, surgery to cure the cancer is usually not an option and the doctor will look at other treatment choices.

*Acknowledge  
and Manage  
Your Pain*

*Early-stage prostate cancer typically is not painful. However, if cancer spreads to your bones, the resulting metastases (not the same as bone cancer) may produce pain. The cause is cancer cells that begin to interfere with the normal health and strength of your bones, often leading to bone pain, fracture, or other complications that can significantly impair your health.*

*If you are experiencing pain, speak to your doctor. Various pain medications and treatments are available. If your doctor is unable to control your pain effectively, you may want to consult with a pain specialist.*

*While you may find yourself on the injured list at times, there is no need for you to experience pain if medication can treat it.*

## *Examine Your Strategies: Treatment Options*

You have taken many important steps in your journey with prostate cancer. Next is to find the best treatment plan for you. Do not feel you have to rush this process. It is critical that you make a careful and informed decision.

If you have been diagnosed with recurrent or advanced prostate cancer, your treatment option may be:

- **Hormone therapy (i.e., androgen deprivation therapy or androgen suppression therapy)**

If you have been diagnosed with hormone-resistant prostate cancer (i.e., your cancer is no longer responsive to hormone therapy), your treatment options to extend life and reduce pain/discomfort may be:

- **Systemic radiation therapy**
- **Chemotherapy**

Other treatment options also may be available to you, which you will want to discuss with your doctor.

# ng the Best Choices

	Treatment Option:	What It Does:	How It Works:
RADIATION THERAPY	<b>External Beam Radiation Therapy (EBRT)</b>	High energy x-rays are administered by a machine outside the body through daily treatment for a course of several weeks.	High energy x-rays are aimed through a single beam at cancer cells.
	<b>3D Conformal Radiation Therapy (3DCRT)</b>	High energy x-rays are administered by a machine outside the body through daily treatment for a course of several weeks.	High energy x-rays are aimed through three beams at different angles to concentrate intensity of radiation at the cancer cells.
	<b>Intensity Modulated Radiation Therapy (IMRT)</b>	High energy x-rays are administered by a machine outside the body through daily treatment for a course of several weeks.	Multiple beams of x-rays are aimed at the cancer cells, allowing the intensity of the radiation to conform to the shape of the prostate.
	<b>Proton Beam Therapy (PBT)</b>	A beam of protons is aimed at the cancer cells by an outside machine during daily sessions for 1 to 7 weeks.	Protons more precisely target cancer cells, allowing for more intense, targeted radiation. Performed in few locations in the United States.
HORMONE THERAPY	<b>LHRH Therapy</b>	Injectible luteinizing hormone-releasing hormone.	Causes a drop in testosterone levels.
	<b>Antiandrogen Therapy</b>	Administration of a drug, antiandrogen.	Action of male hormones, including testosterone and androgens released by the adrenal glands, are blocked.
	<b>Estrogen Therapy</b>	Administration of estrogen hormones.	Lowers testosterone production and may destroy both androgen-dependent and androgen-independent prostate cancer cells.
	<b>P450 Enzyme Inhibitors</b>	Involved in hormone synthesis, including testosterone, that stimulates prostate cancer cell growth.	Can decrease levels of testosterone and adrenal androgens and have direct cytotoxic effects on prostate cancer cells.
CRYOSURGERY	<b>Cryosurgery (salvage therapy)</b>	Technique uses ultrasound-guided placement of cooling probes into the prostate.	Freezes and kills cancer cells. Similar to radiation. Can be combined with hormone therapy to reduce the size of the tumor before freezing. Long-term effectiveness is not well known.
HIFU	<b>High Intensity Focused Ultrasound (HIFU)</b> Medical device piloted by a computer.	Ultrasound treats localized prostate cancer by increasing the temperature (85°C) inside the prostate.	Spinal or epidural anesthesia is used. Probe inserted into the rectum emits a beam of high intensity focused ultrasound destroying targeted cells. Not yet available in the United States. Patients must travel to Canada or Europe for treatment.
CHEMOTHERAPY	<b>Chemotherapy</b>	The administration of powerful drugs, either by mouth, intravenously or intramuscularly.	Drugs circulate throughout the body to kill growing cancer cells. Taxotere® (docetaxel) in combination with prednisone is indicated for the treatment of patients with androgen-independent (hormone-refractory) metastatic prostate cancer. Taxotere is the only new agent approved by the FDA for the treatment of Hormone Resistant Prostate Cancer in decades.



# Your Medical Dream Team: Investigating

While the ultimate goal of prostate cancer research is to find a cure, the focus now is to discover new treatments that increase survival times, delay progression of the cancer, and help to maintain or improve a patient's quality of life (e.g., fewer side effects).

While researchers are working hard on these experimental therapies, only a few will succeed in clinical studies and receive approval by the U.S. Food and Drug Administration (FDA).

Current research includes many various studies, such as:

- **MedImmune's Abegrin™, which may be able to slow the growth and development of prostate cancer metastases by cutting off their supply of oxygen-bearing blood and selectively causing cell death.**
- **Dendreon's Provenge® (sipuleucel-T) represents a new class of active cellular immunotherapies that are uniquely designed to stimulate a patient's own immune system, possibly providing patients with a meaningful survival benefit with low toxicity. Provenge targets the prostate cancer antigen, prostatic acid phosphatase.**
- **Novacea's Asentar™ (DN-101) is a high-dose oral formulation of calcitriol, a biologically active form of vitamin D and a naturally-occurring hormone, which may have the potential to work in combination with Taxotere (docetaxel) to extend survival and reduce some of the side effects associated with chemotherapy.**

Give It All  
You've Got

*"When I became a cancer patient, I considered joining a clinical study. When the time was right, I discussed this option with my doctor. We found a clinical study that was close to my home, and I learned all of the risks and benefits of participating in the study.*

*Obviously, I decided to join the study because I hoped it would benefit me. And if not, I hope it may benefit someone down the road – maybe even one of my own sons." Jim*

# ating Cutting-Edge Therapies

## Clinical Trials

Clinical trials (also called clinical studies) are an important treatment option for you to understand and consider as you manage your cancer. A clinical trial is a research study that is designed to answer specific questions about new therapies or new ways of using known treatments (e.g., Is it safe? Does it work?). Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people.

Information on federally and privately supported clinical studies for a wide range of diseases and conditions being conducted in 50 states and in over 130 countries is available at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). At this federally sponsored free web site, you can find a comprehensive listing of clinical studies for various stages and type of prostate cancer and related issues (e.g., bone metastases, fatigue, urinary incontinence, etc.).

For information regarding emerging therapies and current clinical trials, ask your doctor about trials that may be appropriate for you and/or visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or [www.ustoo.org](http://www.ustoo.org).

### Common Clinical Trial Terms

**FDA:** *The U.S. Food and Drug Administration ensures the safety and effectiveness of all drugs, biologics, vaccines, and medical devices.*

**Clinical Studies:** *Determine if new drugs or treatments are safe and effective.*

**Experimental Drug:** *A drug that is not FDA-licensed as a treatment for a particular condition.*

**Phase I Studies:** *Determine whether a drug is safe and effective in humans.*

**Phase II Studies:** *Evaluate the effectiveness, side effects and risks of a drug for a particular disease in patients.*

**Phase III Studies:** *Confirm effectiveness, safety and benefit-risk relationship of a drug in a larger group of patients.*

# Get Your Head In The Game: Sta

Common  
Concerns—  
And How to  
Address Them

## **Incontinence/Urine Leakage**

*If you are experiencing incontinence and need more information on how to manage this issue, visit [www.ustoo.org](http://www.ustoo.org) and go to the “Post-Treatment Issues” section.*

## **Impotence/Erectile Dysfunction**

*Impotency is widely reported and understandably an emotionally charged and challenging aspect of this disease. However, you do have options:*

- Oral Medication  
(i.e. Viagra, Levitra or Cialis)
- Intra-Urethral Suppository
- Penile Injection
- Vacuum Device
- Penile Prosthesis

*To learn more, have a frank discussion with your doctor. Us TOO also provides UCSF Medical Center’s “Managing Impotence – A Patient Guide” – at [www.ustoo.org](http://www.ustoo.org); search for “UCSF managing impotence.”*

Unchecked persistent or excessive worries, concerns, distress and frustrations can directly impact your physical and emotional well-being. If you are focusing on the negatives, stop and look at the positives. Get your head in the game! Easier said than done? Try some positive thought boosters below, and you may begin to feel better today.

## **Positive Thought Boosters**

- **Avoid violent or depressing movies, books, and television programs. Try some of the new comedies or one of the classics.**
- **Shield yourself from the world’s daily sorrows by going on a “news fast” (i.e. avoid newspapers and broadcast news programs) for at least one week. Assess your experience and perhaps continue indefinitely.**
- **Associate with calm, positive people.**
- **Release any grudges. Rectify any existing relationship problems.**
- **Appreciate nature’s beauty and wonder.**
- **Say positive affirmations daily, including telling yourself that you are loved. Learn to mean it. If you cannot, get professional help to understand why.**
- **List those people and things for which you are grateful daily.**
- **Volunteer your time or renew your commitment to activities that fill you with purpose.**
- **Practice some team spirit – tell or show your loved ones that you love them!**

# Living Positively Emotionally

## Joining an Us TOO Chapter Support Group

Studies have shown that patients who regularly attend support groups tend to live longer than those cancer patients who do not.

Us TOO has over 320 peer-to-peer chapter support groups worldwide that hold regular free meetings for men living with prostate cancer, their family and friends, and health professionals interested in this disease. The meetings provide unbiased information in areas related to prostate cancer, such as surgery, radiation, medications, nutrition, and the many physical and emotional aspects of prostate cancer.

Additional support also is available at 14 online Us TOO discussion groups, called Prostate Pointers. These are some of the most active and popular prostate communities available online, featuring focused and moderated mailing lists, an event calendar, and links to thousands of physician- and lay- contributed web pages.

Because supportive family members play an important role in the health and well-being of the patient, Us TOO created the Circles of Love Companion & Family Member program, and the new Partner's Program Guide. These timely and valuable printed materials, care kits, books, and downloadable tools acknowledge, uplift and support those closest to the patient. Support groups for caregivers, family and friends also can be found in local newspapers, at your cancer center, through your doctor or nurse, and online.

### Finding an Us TOO Chapter Support Group or Online Support Discussion Group

- Visit the Us TOO website at [www.ustoo.org](http://www.ustoo.org).
- You may contact the Us TOO headquarters at 1-800-80-US TOO (800-808-7866).
- In the Chicago area – (630) 795-1002
- Online discussion & support: [www.ustoo.org/Prostate\\_Pointers.asp](http://www.ustoo.org/Prostate_Pointers.asp).

Caregiver  
Self-care is  
Essential

*Your caregivers may not have prostate cancer, or even a prostate, but they are having a very real experience with prostate cancer, so it is critical that caregivers also care for themselves, remembering to:*

- Exercise regularly
- Eat a balanced diet
- Get plenty of sleep
- Reach out for help to their family and friends, an Us TOO chapter support group, or your church
- Continue to do some or all of their favorite activities or hobbies

*The Circles of Love Companion and Family resources are available at [ustoo.org](http://ustoo.org) or by calling Us TOO at 1-800-808-7866*

# Tactical Team Support: Getting

Facing a rising PSA, recurrent cancer or advanced disease is no time to go it alone. While most people immediately focus on the medical team and others immediately assemble their home team, it also can be helpful to have a tactical team for added support.

What is a tactical team? This is a group of people who can help with:

- **Understanding health insurance coverage**
- **Information gathering**
- **In-home care**
- **Chores, homemaking, light housekeeping, and minor house repair**
- **Transportation**
- **Caregiver support**
- **Emotional care**
- **Equipment/adaptive aid services**

Various health and human service organizations and governmental agencies are available to provide different types of support to you and your family. Be aware that services may vary by city and state.

The following list of resources can get you started:

## *General*

- **Your local library and resource specialist**

## *Senior Services*

- **AARP**  
**800-687-2277 (888-OUR-AARP)**  
**[www.aarp.org](http://www.aarp.org)**
- **National Association of Area Agencies on Aging**  
**800-677-1116**  
**[www.eldercare.gov](http://www.eldercare.gov)**

# Additional Help

## Health Insurance

- Centers for Medicare and Medicaid Services  
877-267-2323 TTY: 866-226-1819  
<http://cms.hhs.gov> (go to “Consumers” section)
- Medicare Hotline  
Toll Free Number: 1-800-633-4227  
Internet address: [www.Medicare.gov](http://www.Medicare.gov)
- Health Insurance Association of America  
National Insurance Consumer Helpline:  
Toll Free Number: 1-800-942-4242  
[www.hiaa.org](http://www.hiaa.org)



## Employment

- Americans with Disabilities Act  
1-800-514-0301  
[www.ada.gov](http://www.ada.gov)
- U.S. Department of Labor, Employee Benefits,  
Security Administration (EBSA)  
1-866-444-3272  
[www.dol.gov/ebsa](http://www.dol.gov/ebsa)
- U.S. Equal Employment Opportunity Commission (EEOC)  
1-800-669-4000.  
[www.eeoc.gov](http://www.eeoc.gov)

## Home Care

- National Association for Home Care and Hospice  
202-547-7424  
[www.nahc.org](http://www.nahc.org)
- Visiting Nurse Associations of America  
888-866-8773  
[www.vnaa.org](http://www.vnaa.org)

## Hospice

- National Hospice and Palliative Care Organization  
800-658-8898  
[www.nhpco.org](http://www.nhpco.org)

# An All-star Fitness Plan: Maxim

Books on Dietary Guidelines for Men with Prostate Cancer

## ***Eating Your Way to Better Health: The Prostate Forum Nutrition Guide***

by Charles E. (Snuffy) Myers, Jr., M.D.; Sara Sgarlat Steck, R.T.; and Rose Sgarlat Myers, PT., Ph.D.

## ***Promoting Wellness for Prostate Cancer Patients***

by Mark A. Moyad

## ***The Prostate Cancer Protection Plan: The Foods, Supplements, and Drugs That Could Save Your Life***

by Robert "Bob" Burns Arnot, M.D.

## ***The Prostate Diet Cookbook: Cancer-Fighting Foods for a Healthy Prostate***

by Buffy Sanders

**Before beginning any new exercise regimen, check with your doctor first.**

Eating a healthy well-balanced diet and exercising regularly not only can improve your overall health but also can help your body better fight cancer.

Regular exercise can:

- Provide important nutrients to your body
- Bring your body to its optimum weight
- Increase your energy and stamina
- Reduce stress
- Improve or reduce treatment side effects

## ***Step up to the (Dinner) Plate***

Some people pay more attention to the quality of the fuel they put in their car than the food they put in their mouth. Now, more than ever before, it is critical to pay close attention to your diet, following these simple guidelines:

- Eat foods high in antioxidants, which may contribute to reducing cancer and heart disease, such as
  - Beta-carotene – sweet potatoes, carrots, cantaloupe, squash
  - Lycopene – tomatoes, watermelon, guava, papaya, apricots
  - Vitamin C – certain fruits and vegetables, cereals, beef, poultry, fish
  - Vitamin E – almonds, nuts, broccoli, safflower and corn oils
- Reduce your sugar and fat intake
- Consume more deep-water fish (e.g., yellowfin tuna, sardines, cod or haddock) and less red meat
- Talk to your doctor about other diet modifications



# izing Your Overall Health

## Condition Your Body

- Walking
- Weight resistance exercises
- Yoga/Pilates
- Stretching
- Tai chi
- Meditation
- Trampoline (small rebounder)
- Exercise bike
- Treadmill
- Rowing
- In-line skating
- Elliptical trainer

## Keeping Your Bones Healthy

Hormone therapy sometimes can lead to bone fractures, which may result in hospitalization and reduced mobility. The inability to exercise due to these fractures only makes matters worse by negatively impacting bone density and reducing overall muscle tone and fitness. Therefore, maintaining bone health is a critical part of your prostate cancer management. While your doctor will treat your bone integrity issues with medicines called bisphosphonates, there are also things that you can do to track and maintain your bone health:

- **Before treatment, measure your height in a doorway and continue to measure it regularly throughout your treatments. Report any height loss to your doctor.**
- **Prior to treatment, demand a bone density test.**
- **If you have already started treatment, look at your medical records for past measurements and begin to record new ones.**
- **Consume your daily dietary intake of calcium and vitamin D to promote bone health, and spend 15 minutes in the sunshine to add to your daily requirement of vitamin D.**
- **If there is pain that lasts more than 7 to 10 days, see your doctor. Do not wait or “tough it out.”**
- **Lift weights or integrate other weight-bearing exercises into your daily activity.**

For a free booklet on bone health, visit [www.ustoo.org](http://www.ustoo.org).

# Worksheets: Doctor's Appointment

Date:

Dr's Name:

## Questions for Your Doctor (General)

- At what stage is my prostate cancer?
- Is the cancer still localized to the prostate gland or has it spread? If so, to where has it spread?
- What are my chances of responding to treatment?
- What are the treatment options for my stage of prostate cancer?
- Are there other treatment options available?
- What are the benefits and risks of the type of therapy you are recommending?
- What are the short-term and long-term side effects associated with the type of therapy that you're recommending?
  - Will it make me sick?
  - Will I develop incontinence?
  - Will it cause impotence (erectile dysfunction)?
  - Will I be able to remain active?
  - Will it affect my appearance?
  - If so, what are the solutions?
- What types of hormonal therapies are available to me? Will these be beneficial?
- What can you tell me about new experimental treatment options?
- Should I consider participating in a prostate cancer clinical trial? Where can I find information about clinical trials?
- Can you provide a referral to a colleague or another expert for a second opinion?
- What can I do to improve the success of the treatment?
- What kind of follow-up can I expect after treatment?
- Where can I get further information on prostate cancer?
- Where can I find additional support?
- What are some support groups/services for prostate cancer patients?

Notes

Photocopy  
worksheets  
for next  
appointment

# Worksheets: Urologist Appointment

Date:

Dr's Name:

## Questions for Your Urologist

### Diagnosis

- What is the PSA value?  
NOTE: a rapid increase in PSA value is usually a warning indication requiring further investigation.
- What is the Gleason Grade? (Obtain the two part-breakdown. For example, is it 3 plus 4 or 4 plus 3?)
- How many biopsy cores were taken?
- What percent of each core was cancerous?
- What are the locations of each biopsy?
- How close to the margin (peripheral border of the prostate) were the positive biopsies?
- What did my CAT Scan indicate?
- What did my Bone Scan indicate?
- What did my MRI Scan indicate?
- Do you think there is any Seminal Vesicle involvement?
- What would you estimate are the chances that the cancer is contained within the prostate? (Doctors use the Partin Tables to make this assessment.)

Go to next  
page for more  
urologist  
questions

Notes

# Worksheets: Urologist Appointment

Date:

Dr's Name:

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## Questions for Your Urologist

### Treatment

- What treatment would you recommend?
- Why do you prefer this treatment?
- What are the side effects of this treatment?
- What are the chances (percent) I will have this/these side effects?
- If I select surgery, would you recommend nerve sparing for me? (If the doctor says "yes," then ask: Bilateral (both sides spared) or Unilateral (one side spared)?)
- How many of these procedures have you done?
- Why do you recommend this option?
- Would you recommend Active Surveillance?
- Are there any other treatment options appropriate for me? If the Dr. says radiation, then ask:
  - Which type of radiation, External Beam, or Seeds (Brachytherapy)?
  - What are the advantages and disadvantages of each type?
  - Regardless of which he/she suggests, ask why not the other form of radiation?
  - What about a combination of both Seeds and External Beam radiation?
  - What are the side effects of each radiation choice?
  - Are they long-term or short-term side effects?
  - What is the probability of any of the side effects occurring with each one of these choices?
  - If I select radiation, would you recommend hormone treatments with the radiation?
- I plan to consider my options. In the interim, would you suggest I have a hormone shot?  
NOTE: This may affect any new PSA reading before your treatment.

## Other

- You may also ask this specialist the same questions about whether you should have an MRI or bone scan.
- At this juncture, you should inform your urologist that you would like to have a consultation with a Radiation Oncologist.
  - Which Radiation Oncologist would you recommend?
  - Does he/she have much experience treating prostate cancer patients?
  - Does he/she do both External Beam and Seed Implant Radiation?
  - How long has he/she been doing Seed Implant Radiation? External Beam Radiation?
- You also should discuss with your Urologist a desire for a consultation with a Medical Oncologist to explore the appropriateness of chemotherapy.

Notes

Active Surveillance

Active Surveillance also called “watchful waiting” means you decide to have no active treatment but will have the choice later to change your mind and begin treatment. During Active Surveillance your doctor should continue to follow you closely and perform digital rectal exams, PSA tests and repeated biopsies to monitor any disease progression or changes.



# Worksheets: Radiation Oncologist

Date:

Dr's Name:

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## Questions for Your Radiation Oncologist

- What treatment, if any, should I have?
- If he/she recommends a Radical Prostatectomy (surgery), ask why.
- If he/she recommends radiation, proceed as follows:
  - What would you estimate are the chances that the cancer is contained within the prostate? (The doctor uses the Partin Tables, but you want his opinion and interpretation.)
  - Which type of radiation, External Beam, or Seeds (Brachytherapy) do you recommend?
  - Regardless of which, ask why not the other form of radiation?
  - What about a combination of both Seeds and External Beam radiation?
  - What are the side effects of each radiation choice?
  - Are they long-term or short-term side effects?
- What is the probability of any of the side effects occurring with each one of these choices?
- If I select radiation, would you recommend hormone treatments with the radiation?
- Would you recommend Active Surveillance?
- How many prostate cancer patients have you treated this way?

# Appointment



Notes

# Worksheets: Medical Oncologist

Date:

Dr's Name:

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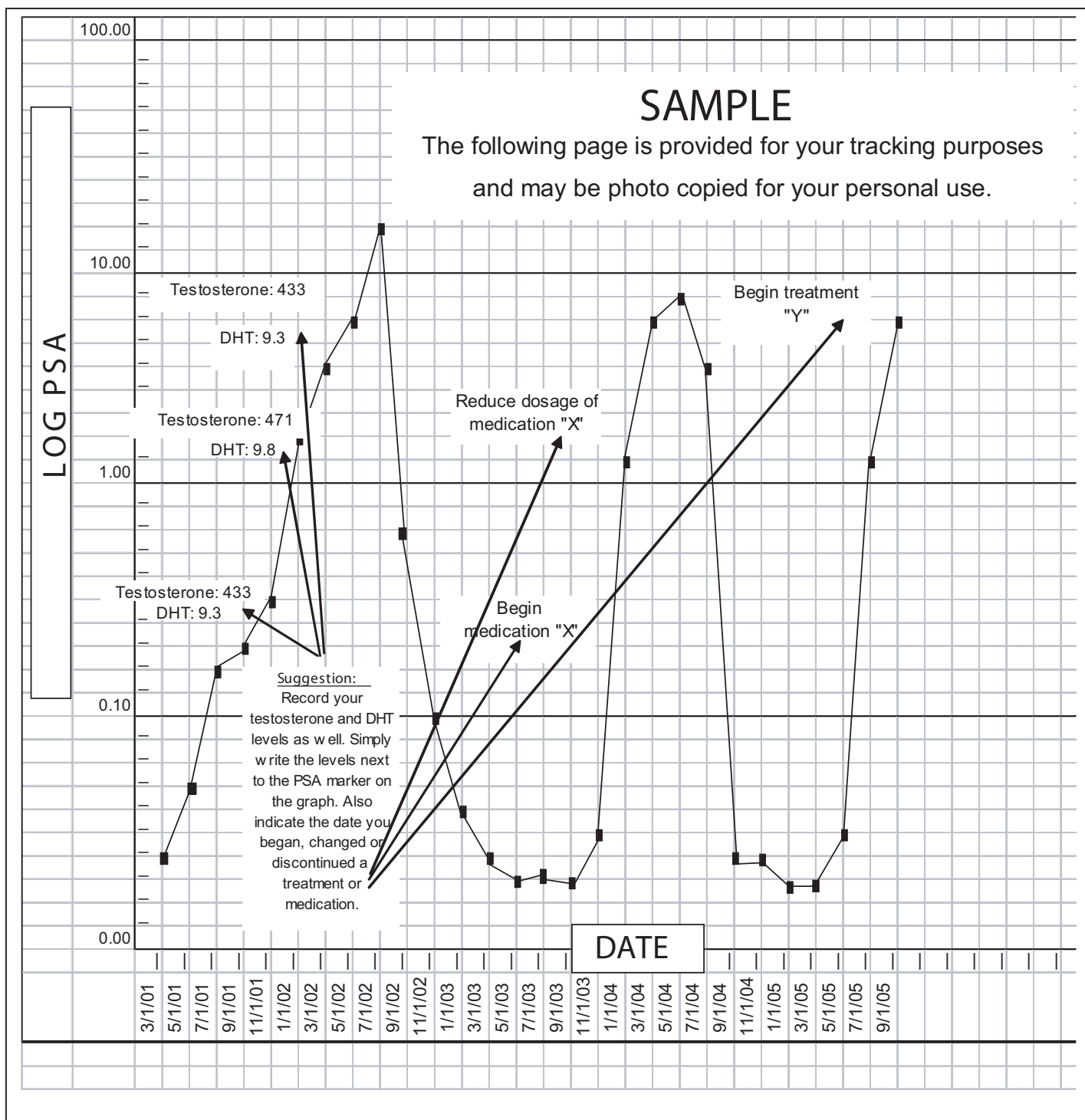
## *Additional Questions for Your Medical Oncologist*

- What treatment would you recommend?
- Why do you prefer this treatment?
- How many men have been on this protocol or used this treatment?
- Am I a candidate for chemotherapy?
- How long will I be getting chemotherapy?
- How will we know if it's working?
- What are the usual side effects of the chemotherapy you recommended?
- Is there any way to make these side effects more manageable?
- How long do the side effects last? Are any permanent?
- How will this chemotherapy affect my prognosis (outlook) for cure or long-term survival?
- Will I still be able to work during treatment?
- Is there anything I should do to prepare for chemotherapy?
- Are there any clinical trials you recommend for me?

# Appointment

Notes

# Worksheet: Tracking Tools



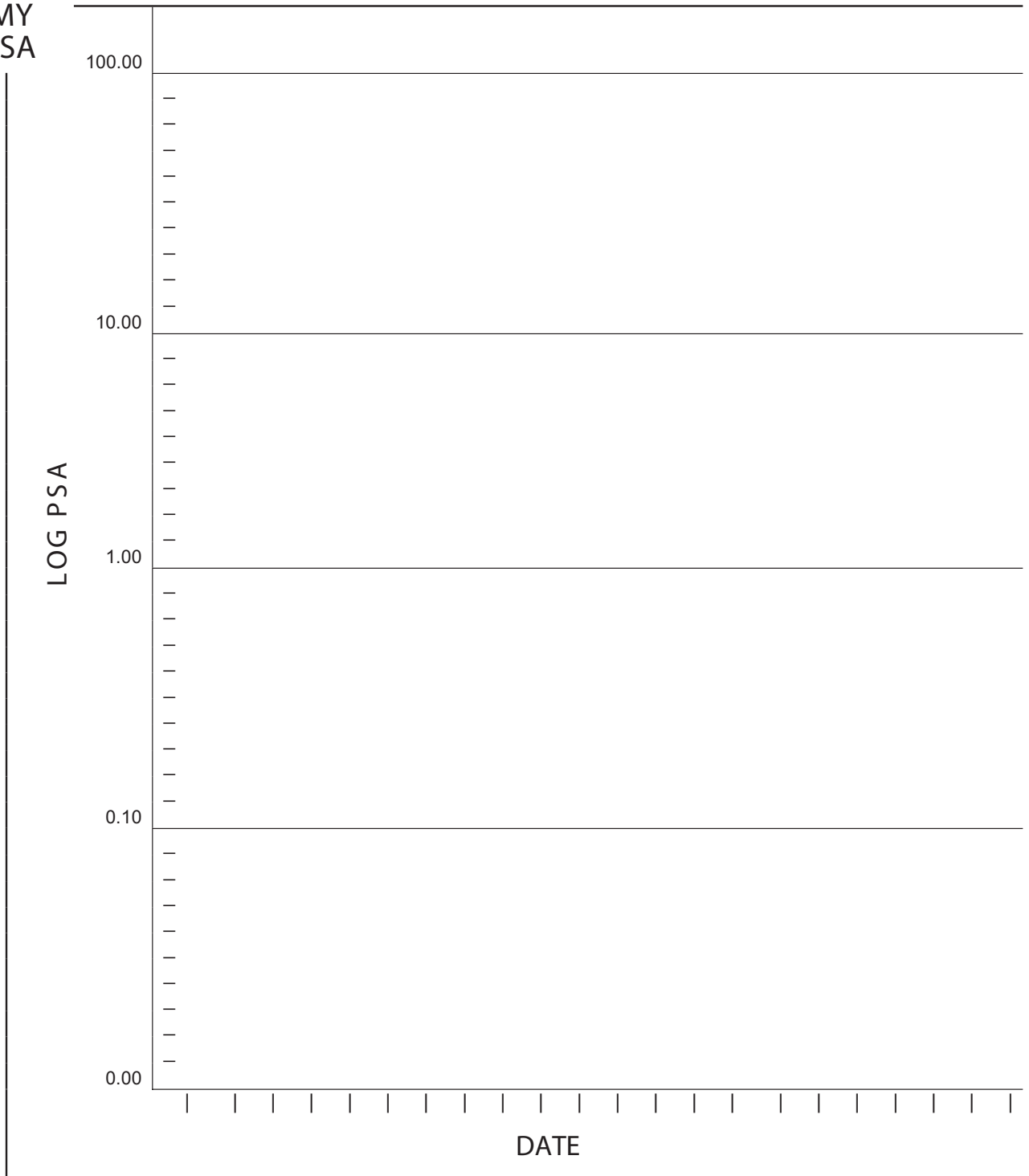
Tracking things like your PSA level, testosterone and dihydrotestosterone (DHT), as well as the timing of changes in treatments or medications, can reveal patterns or cycles. This can be very helpful for you and your doctor as you try to understand the status or progression of your prostate cancer, allowing you and your doctor to respond accordingly.

Name: \_\_\_\_\_

From: \_\_\_\_\_

To: \_\_\_\_\_

MY  
PSA



This table is for your tracking purposes. You can record your progress here or make copies of this page to use over and over.



Notes



# Cure to Comfort: You Still Have

While we always hope for long-term survival, there may come a time when this is no longer the case. Some patients and their families will find themselves mentally and emotionally downshifting from an intense daily regimen of treatment to the quiet delivery of comfort.

If you have reached this phase of your life, you and your loved ones still have options, and a discussion with your doctor about your quality of life can lead you to local palliative and hospice care resources.

An interdisciplinary hospice team (e.g., your doctor, hospice physician, nurse, home health aide, social worker and others) will have several major resources to support you and your loved ones, including:

- **Managing the patient's pain and symptoms.**
- **Assisting with the patient's emotional, psychosocial and spiritual needs.**
- **Providing needed drugs, medical supplies, and equipment.**
- **Coaching the family on how to care for the patient.**
- **Delivering special services, like speech and physical therapy, when needed.**
- **Making short-term in-patient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time.**
- **Providing bereavement care and counseling to surviving family and friends.**



## **Hospice/Palliative Care: For More Information**

**Call the National Hospice and Palliative Care Organization Helpline at 1-800-658-8898 or visit [www.nphco.org](http://www.nphco.org) for free consumer information on local hospice programs.**



*Someone to talk to...  
who understands!*

Us TOO International, Inc. based in suburban Chicago, is a grassroots organization that was started by prostate cancer survivors in order to communicate timely and reliable information to men with prostate cancer, their spouses/partners and families, enabling them to make informed choices regarding the detection and treatment of prostate cancer.

Started in 1990, Us TOO today offers many programs and services designed for both men with prostate cancer and their loved ones.

Us TOO has the most extensive network of patient and family support with one of the most active and popular prostate communities available online – Prostate Pointers, and over 320 chapter support groups worldwide.

To learn more, visit [www.UsTOO.org](http://www.UsTOO.org) or call 1-800-808-7866.

**Us TOO International, Inc.**

Prostate Cancer Education and Support Network

5003 Fairview Avenue

Downers Grove, IL 60515 (USA)

**Phone:** (630) 795-1002

**Fax:** (630) 795-1602

**PCa Support Hotline:** (800) 80-Us TOO (800-808-7866)

**Email:** [ustoo@ustoo.org](mailto:ustoo@ustoo.org)

**Office hours:** Monday – Friday, 9 AM -5 PM Central Time