

Principles for Managing
**Advanced
Prostate
Cancer**





This guide is dedicated to
Bill Blair
who founded an Us TOO support group
created specifically to help men with
advanced, or metastatic, disease –
hence the group's name, *Mets Mavericks*.
Bill spent countless hours on the phone each day
speaking to people from all over the country.
He encouraged them, advised them, and inspired them
with the hope and information they needed
to cope with their situation.
He never turned away from anyone who needed his help.
Bill Blair passed away on February 23, 2009
but only after making his indelible mark of
wisdom and empowerment that will be forever apparent
in those he touched who now touch others; and so on it goes.
As Bill often said,
"We honor the fallen by serving the living."

Principles for Managing
**Advanced
 Prostate
 Cancer**



**Us TOO International
 Prostate Cancer Education
 & Support Network**

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Greetings,



If you or someone you care about has been battling prostate cancer and the disease has advanced or is now advancing, Us TOO is made up of a network of survivors and partners who understand the questions to be answered and the new challenges to be addressed. Of course, being diagnosed with advancing prostate cancer is a serious condition. But it's important to recognize that the situation can be hopeful with more treatment options now available than ever before, along with new drugs that have been approved recently, with more on the way.

This guide was created to provide perspective and advice from some of the people who are living with advancing prostate cancer. The intent is not to answer all of your questions. Rather, we're outlining a path that you may choose to follow which may be helpful in making some tough decisions about managing and treating the disease. Knowledge is power. A positive attitude and the confidence gained from knowledge are valuable assets in the fight against prostate cancer.

Possibly the most valuable resource for many people who are battling advancing prostate cancer is participation in a local support group where there's an open exchange of dialogue among prostate cancer survivors. There have been several instances when a physician has determined that nothing more could be done for a man who then joined a support group and found other survivors who referred him to a life-saving specialist and treatment.

Us TOO has 325 support group chapters throughout the United States and in numerous cities around the world that provide the platform for collaborating with other survivors and their family members who have walked the same path and can offer valuable information, perspective and hope. We've been providing free resources for every phase and aspect of prostate cancer for more than 20 years. Beyond the contents and additional resources contained in this guide, our website at www.ustoo.org provides an immense amount of information including locations for support group meetings, the Us TOO Inspire Online Discussion Community, Prostate Pointers, and My Prostate Cancer Roadmap. Plus, there's the Us TOO PCa HelpLine at 1-800-80-UsTOO (1-800-808-7866).

Please let us know how we can be of further assistance to you as you navigate through this information to help determine the best path of treatment for managing your advancing prostate cancer while maintaining the highest possible level for your quality of life.

Sincerely,

A handwritten signature in blue ink that reads "Thomas N. Kirk". The signature is fluid and cursive, written in a professional style.

Thomas N. Kirk
President & CEO
Us TOO International
tom@ustoo.org

Knowledge is Hope.

We'd Like to Help You

Over the years Us TOO International Prostate Cancer Education & Support Network has developed numerous educational resources that have helped thousands of people to more effectively manage their advancing prostate cancer. We'd like to share with you some of our learning. We'd like to teach you how to get the information you need to make smart decisions about the best approach for your disease management.

“Experience the passion and joy that comes from helping others and allowing oneself to enjoy others who are helping and caring for you.”

Bill Blair

All Us TOO activities are supported by donations from corporations and people like you.

Find additional information at www.ustoo.org or call 800-808-7866, or 630-795-1002



Support for You!

To Know the Road Ahead Ask Those Coming Back

The mission of Us TOO is to help men and their families make informed decisions about prostate cancer detection and treatment through support, education and advocacy. Inspired by the progress made in the fight against breast cancer, the grassroots 501(c)3 non-profit organization was founded in 1990 by five prostate cancer survivors and their families who recognized that “cancer affects us, too.” Us TOO now has 325 support group chapters throughout the United States and other countries that provide free resources for every phase and aspect of prostate cancer.

Us TOO
PROSTATE CANCER
EDUCATION & SUPPORT

Throughout this guide you'll find green boxes such as this one with information that we like to think of as "tips from the field." Know that these techniques are not scientifically proven to be effective or meant to be medical advice; rather, they're just suggestions that have worked well for other people and may work well for you, too.

Along with acknowledging the advancement of your disease, also acknowledge the advancement in current treatments and future possibilities that offer real hope for effectively managing advancing prostate cancer. Many of the men who attend Us TOO support groups have been successfully managing the treatment of their advancing disease for ten or 15 years; and a few for more than 20 years.

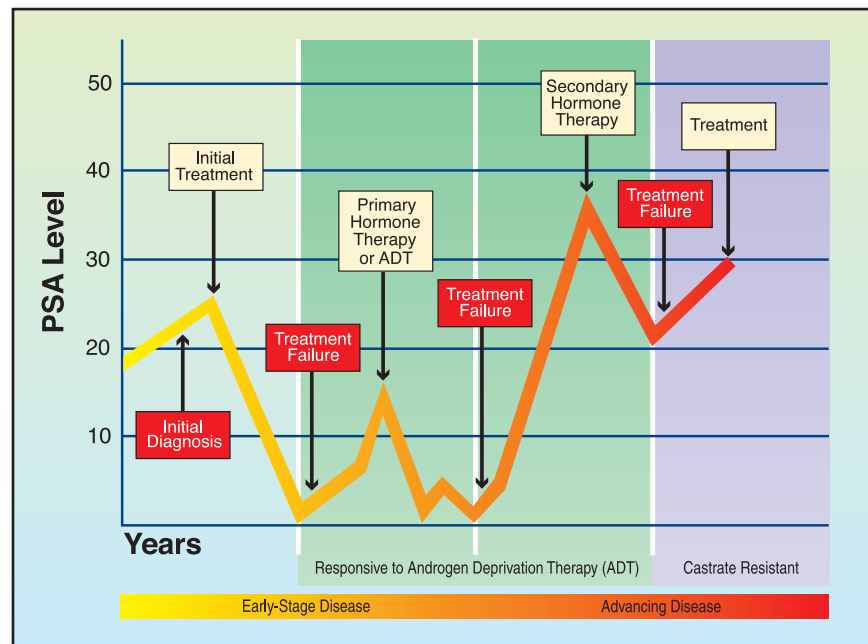
Your Advancing Prostate Cancer

A man can have prostate cancer for many years without the cancer ever advancing. And on the opposite end of the spectrum, occasionally an initial diagnosis can be that of advanced prostate cancer. You are at an increased risk for developing advancing prostate cancer if the cancer cells have spread outside the capsule of the prostate gland to the seminal vesicles or tissues around the prostate, but not to the lymph nodes. This disease state is technically defined as **Stage III prostate cancer, or localized advanced prostate cancer.**

Your Disease is Advancing if:

- Prostate cancer cells have metastasized to lymph nodes or to organs and tissues far away from the prostate such as the bone, liver, or lungs, technically defined as **Stage IV prostate cancer, or metastasized prostate cancer.**
- or -
- **PSA (prostate-specific antigen)** has risen three consecutive times after completion of the primary treatment in response to the initial diagnosis for prostate cancer, or while on androgen deprivation therapy (ADT), indicating that the **therapy is no longer working and the disease is castrate resistant.**

This guide is focused primarily on Stage IV or castrate resistant prostate cancer. Most likely your current disease state can be found along some point of the graph below, which illustrates the disease progression of prostate cancer that is advancing.



Learning to Cope through Knowledge and Hope

We recognize that the vast majority of people battling advancing prostate cancer are already familiar with the basics about the disease, diagnosis, and treatments.

So we've assembled a team of people at Us TOO who've been directly affected by prostate cancer to help develop this material for you. These are real people who tell it like it is and offer you guidance based on what's worked well for them or someone they have known personally. They cut to the chase and share their wisdom and experience specific to the issues faced by someone with advancing disease. Additionally, there are many other people who are also very knowledgeable and experienced within the Us TOO network of local support groups. Seek them out as well.



Fred Gersh

Battling prostate cancer since 1989 with external beam radiation and hormonal therapy following a radical prostatectomy; managing his advancing disease since 2009 with chemotherapy; active in prostate cancer advocacy groups; has led the Us TOO support group in Alexandria, VA since 1991 and serves as an Us TOO volunteer Regional Director. fmgersh@cox.net



Jerry Hardy

Us TOO board member diagnosed with prostate cancer in 2001 at the age of 46; member of Us TOO chapter in Livonia, MI; peer reviewer for National Cancer Institute; with his wife, Jo Ann (a former Us TOO board member), has focused advocacy efforts on intimacy issues surrounding the disease. motownjerrylee@aol.com



Fred Mills

Us TOO International Chairman of the Board and health care executive; diagnosed with prostate cancer in 1997; effectively managed disease through surgery and intermittent hormone therapy. fred.mills@praxismedical.net



Russ Gould

russgould@aol.com

Diagnosed with prostate cancer in 1997; currently managing advancing disease with second line hormonal therapy and leading an advancing disease support group for Us TOO and Wellness Place in Palatine, IL; member of NIH prostate cancer research team.



Jim Kiefert, EdD

Diagnosed with prostate cancer in 1989 at the age of 50; managing advancing prostate cancer with Provenge immunotherapy after initially having surgery and radiation; He established Us TOO support groups in The Dalles, OR and Olympia, WA. jimkiefert@aol.com



Charles "Snuffy" Myers, MD

<http://www.prostateteam.com/patient-questions.php>

President of the Foundation for Cancer Research & Education; diagnosed with prostate cancer in 1999 and treated with lymph node surgery, radiation therapy, and intermittent hormonal therapy.



**Shirley Grey,
RN, MSN**

sgrey@communicationscience.com

Business executive and registered nurse; established Us TOO partners support group in Palatine, IL to help others by sharing her experience of being at the side of her husband, Herbie, who was diagnosed with prostate cancer in 1991 and passed away in 2008.



**Kay Lowmaster,
MSW, LCSW**

Us TOO Vice Chairman of the Board and oncology clinical social worker at UPMC Cancer Centers; has led Us TOO support group in Pittsburgh, PA since 1995; serves as faculty member for several Us TOO University programs and an Us TOO volunteer Regional Director for OH, PA and WV. lowmasterkl@upmc.edu



Paul F. Schellhammer, MD

Fellow American College of Surgeons, Past Chairman of American Urological Association; diagnosed with prostate cancer in 2000 and had a prostatectomy followed by external beam radiation and androgen deprivation therapy. PSchellham@aol.com

Learning to Cope through Knowledge and Hope

...continued

We're not just talking about Us TOO... we're showing how we provide service and support with real-world advice from people who've been managing advancing prostate cancer for years.

We're not just talking about options... we're sharing our principles and some of the lessons we've learned from our experience to help empower you.

The Us TOO team shares knowledge gained from the experience of collectively having managed prostate cancer for more than 100 years. They've invested countless hours helping thousands of people in their fight against the disease, and can credibly speak to a wide range of situations, treatments and side effects. Some were diagnosed during the early stages of the disease and underwent surgery and radiation. Some had an initial diagnosis of advanced prostate cancer that had spread beyond the prostate. Some have prostate cancer that has evolved and are on androgen deprivation therapy, or are castrate resistant and are on chemotherapy. Some have lost a spouse to prostate cancer. All of them have lost friends to the disease and can personally relate to the fact that **prostate cancer kills more than 30,000 men each year.**

This guide will help teach you and your loved ones how to manage advancing prostate cancer with core principles of empowerment to take control of managing the disease and maintain a high quality of life. It is modeled after the information and structure that has proven to be effective in the Us TOO support groups for those with advancing prostate cancer.

When you take control of managing your disease, you accept an awesome responsibility. There's an incredible amount of information you need to know in order to do your job effectively. And as the old saying goes, "You don't know what you don't know." In order to be informed and stay current, access the typical information sources: web sites, online discussion communities, books, magazine articles, and, of course, talk with your doctors and nurses. A positive mindset is critical for success. Always be looking for new resources to build your knowledge and your team.

"Where the mind goes... the body follows."

Bill Blair

Pickles



Learning to Cope through Knowledge and Hope

...continued

Enlist the help of others by attending an Us TOO support group meeting. Through peer-to-peer interaction, you'll give and take valuable information from personal experiences with advancing prostate cancer and benefit from the collective knowledge of everyone in the room. In addition to the technical expertise specific to the disease, you'll also find the invaluable benefit of human interaction—concern, support, and commitment—to help each person in the group work toward whatever solution is best for him at whatever point he's at in the management of his disease. Members of your local Us TOO support group can help you with every principle we'll cover in this guide.

Empower
Yourself!

Taking charge of effectively managing your advancing prostate cancer may include educating your doctors at times. Doing so isn't necessarily a slam against the competency of your doctor. He or she is obviously busy doing a job that doesn't leave a lot of time for keeping current on every aspect of the latest information about the disease and its treatment. Many people who attend Us TOO support group meetings share various stories about informing their doctor; and doctors will often commend support group members for being much more knowledgeable about advancing prostate cancer than the vast majority of patients.

Take
Control!

“Although it would be great, you're not going to find one resource to provide you with the convenience of 'one-stop shopping,' or one person out there who's going to be your 'answer man' for everything you need to know about managing your advancing prostate cancer.

“You must do the work to get the information and piece it together for a plan that's best for you and your individual circumstances. Although it can be exhausting, make no mistake—you must direct the management of your disease to optimize the outcome and maintain the highest quality of life. But that doesn't mean you should do it all by yourself.

“You need a team of people to help you. But you are in charge. We know that people who are actively engaged in their care will live a longer and fuller life.”



Russ Gould

Learning to Cope through Knowledge and Hope

...continued

**“Knowledge
is power.”**

Bill Blair

Commit to an action-oriented process for making decisions and **be ready to work hard** at finding the best treatment for you to manage your disease and maintain the highest quality of life. Assemble a team of family, friends, support group members and physicians to help you. Stay current with the latest materials being written about managing advancing prostate cancer. For example, read Shirley Grey’s “Ten Things I Learned While Loving in Sickness and in Health” (find web site link on page 39) in which she shares her heartfelt advice and some of the wisdom she acquired while at the side of her husband during his 17-year battle with prostate cancer that he lost in 2008.

**Value
Humor!**

And finally, remember the **power of laughter**. Humor can soothe and heal tender hearts. Throughout this guide we’ve included comments and quips intended to **make you smile**. We suggest that not laughing because your life isn't going the way you would prefer gives prostate cancer far more power and control over you than you should allow it to have.

Take Control of Managing Your Disease With These 7 Principles of Empowerment:

1. Chart Your Disease Data
2. Assess Your Disease State
3. Identify Your Treatment Options
4. Develop and Reassess Your Treatment Plan
5. Anticipate Side Effects and Know How to Manage Them
6. Recognize the Eventual Need for an End-of-Life Plan
7. Empower Yourself Daily through Diet, Exercise, Spirituality and Humor

**Let's
get
Started!**

Chart Your Disease Data

1.

If you haven't already developed a system for keeping a **detailed account of your medical history** and test results to monitor your disease progression, you need to **start now, and be disciplined to update it as needed**. The details are important in your disease management.

Organize all of your medical documents in an accordion folding file with divider sections that can be used for separating surgical reports or lab results from tests such as x-rays and bone scans. It can also be helpful for collecting medical expense receipts, recapping notes from doctor visits, and keeping information for future support group meetings, doctor appointments, or seminars/webinars.

In addition to keeping files with copies of all medical records and test results, create one or two documents that summarize your disease progression and your current status. Not only is this summary helpful for you at a glance, it's imperative for **each** of the physicians on your medical team to have a concise and comprehensive recap of your treatment regimen and be able to reference any data they may need to help monitor your treatment in their area of specialty.

Pay attention to the details. Keep records of your test results, medications, diet changes, and medical procedures. Your life depends upon it.

“It’s been my experience that the type of guys who do well managing their disease are those who pay attention to details while taking charge of their lives and treatment. The guy who doesn’t do as well turns over too much responsibility to others, or puts too much trust in having ‘the best’ medical team. Rather than ask the questions to empower him to take charge of his disease, he entrusts the responsibility of his disease management to others with an attitude of ‘whatever you say, doc.’

“As an example, every time I have an appointment with my doc the nurse takes me into a room where she checks my blood pressure, temperature, weight, etc. I hear her put my chart in the rack on the outside of the door. I wait until I hear my doctor take the file from the rack; and literally 90 seconds later he enters the room and starts the discussion.

“Think about it. How much time does your doc take to review your file? He or she probably sees 20 to 40 patients in a day. YOU must know your chart and condition. YOU need to have your lab results and know what your options are and discuss them with your medical professional.”



Jim Kiefert

1. Chart Your Disease Data

...continued

**Create
Tools!**

Adopt a systematic way of managing your life with advancing prostate cancer and managing your disease. Here are a few suggestions for structuring your reporting system to summarize the most important information to track your disease history and progression. On your first appointment with a new doctor, **bring these summary reports along with your folding file of all medical reports and test results.**

Create a data table to record each of your test results. This can be done manually on paper or as a computer document that can be easily updated. List the various tests in the first column. In the next column note the normal ranges for the tests results. Then record your test dates and results/notes for each in the following columns to the right. The chart below lists a few common tests.

| TESTS | NORMAL RANGE | TEST DATE/RESULTS | TEST DATE/RESULTS | TEST DATE/RESULTS | TEST DATE/RESULTS |
|-------------------------------|--------------|-------------------|-------------------|-------------------|-------------------|
| PSA | | | | | |
| Testosterone | | | | | |
| Dihydrotestosterone (DHT) | | | | | |
| Circulating Tumor Cells (CTC) | | | | | |
| Complete Blood Count (CBC) | | | | | |
| Urine | | | | | |
| Bone Density | | | | | |

In addition, keep a record of all prescription drugs, over-the-counter drugs, supplements, and vitamins that you take and use a pill organization box for your medication. Track the dosage, start date, and stop date, if applicable. Also note why you are taking each. Have a system in place to monitor your dosage and timing to avoid any mistakes that could be deadly. Build in checks and cross-checks and be aware of interactions between drugs, supplements, and diet.

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

See the back of this publication for a convenient blank chart that you can customize for your tests and medications.

Chart Your Disease Data 1

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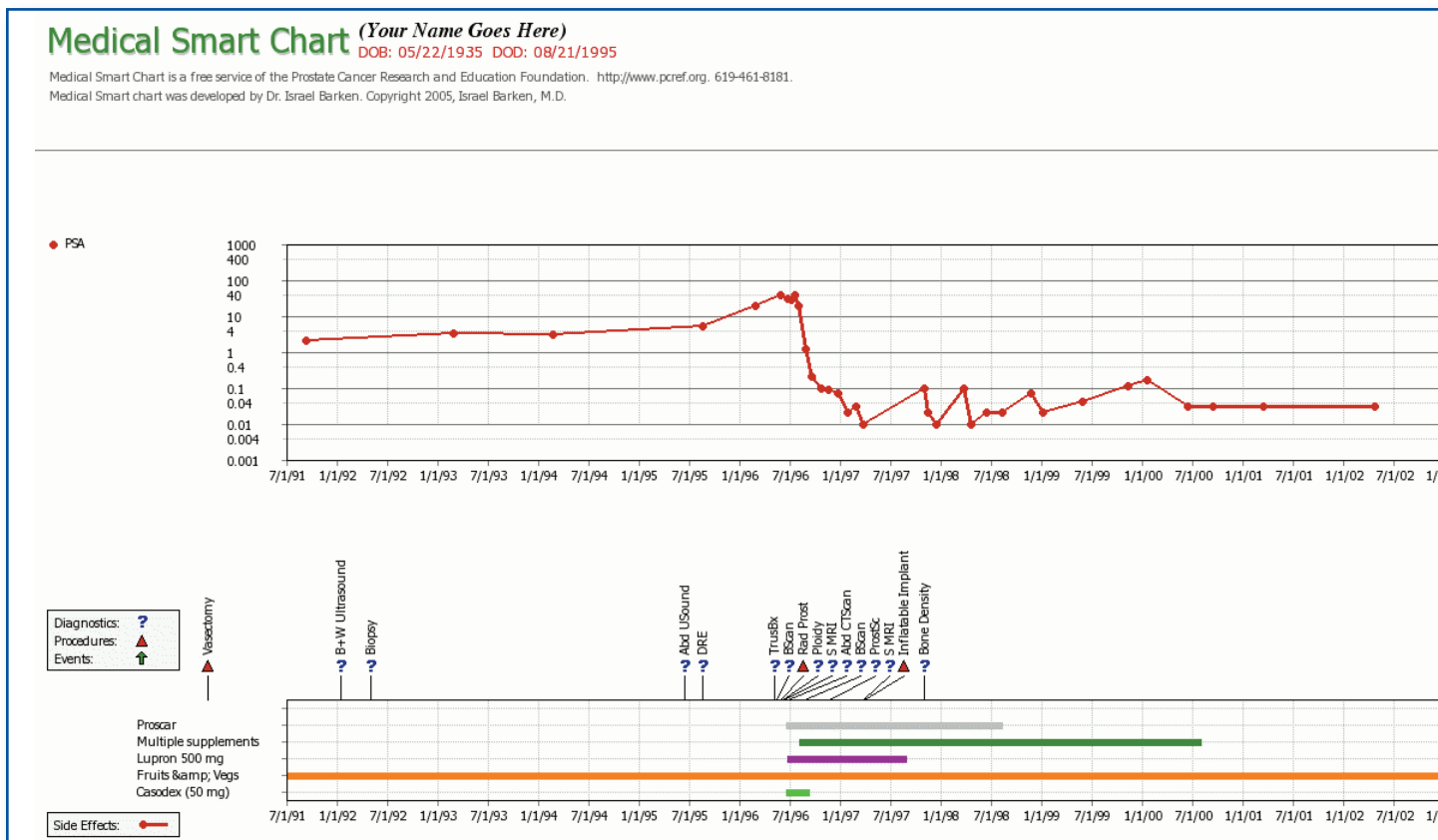
Another helpful tool that you can **create** is a **timeline chart** that provides dates across the bottom (x-axis) and PSA ranges up the side (y-axis). Note specific dates of PSA tests and corresponding PSA levels.

It's also a good idea to **create another chart** directly below the first to mirror the same timeframe. Use this chart to **capture important dates/results for other diagnostic tests or medical procedures** and note the office, hospital, or clinic where your test materials and results are located (i.e.: tissue samples, etc.) if they aren't in your file. In addition, record the timeframes for medications, vitamins, and special diets. Reviewing the two charts together **provides a more complete snapshot for monitoring the progress of your treatments.**

The graphic below shows the basic structure of the two charts. Special thanks goes to Israel Barken, MD for allowing us to include this resource. It can also be accessed electronically at:

www.pcref.org/sample_graph2.php

If this level of detail is too overwhelming for you or if you're just not a "detail guy," request the assistance of somebody who is into the details and willing to help you.



See the final page of this publication for a blank Medical Smart Chart form that you can use to help monitor your progress.

2. Assess Your Disease State

Since there is no cure for prostate cancer after it's metastasized, the long-term goal is to **effectively manage the disease** through treatments that halt its growth—or at least slow it down as much as possible. **Assessing the progression of advancing prostate cancer is gauged primarily by a rise in the PSA level.**

Did you know that after a radical prostatectomy, a rise in PSA doesn't necessarily confirm that the disease is advancing? The first thing to do in that situation is to have a DRE (digital rectal exam) to palpate the prostate bed. It's possible that a portion of healthy prostate tissue remained after the surgery and has started to produce PSA. If this is the case, careful monitoring over subsequent months will show PSA levels that go up initially and may trend upwards gradually over the years.

It is possible that a slow-growing cancer may also produce the same effect. But neither situation would warrant radiation, which is the typical rapid response to a rise in PSA level after a radical prostatectomy. If the cause of the rise in PSA is due to advancing prostate cancer, PSA levels will increase exponentially over a short time and the disease can be treated accordingly. Before you decide to pursue any follow-up treatment, be aware that there are situations that **may initially seem to indicate a relapse but may not be cancer at all.**



Fred Mills

If you still have your prostate, your physician should always draw your blood to measure the various markers before doing a DRE since it can stimulate the production of PSA and **give a false reading.** Avoid ejaculation within 24 hours prior to the PSA test as it can also increase PSA levels temporarily.

“In addition to PSA, the routine blood test can measure testosterone and dihydrotestosterone, or DHT, known as the ‘jet fuel’ for prostate cancer. Surprisingly, many doctors aren’t measuring all three, nor do they typically use all of the information for treatment recommendations. Make sure that your doctor measures levels for all three markers and ask him or her for the results from each test.

“Some doctors may resist doing a DHT test more frequently than once every six months since that’s the limitation that’s been established for Medicare coverage. But if it’s important to you, offer to pay for it yourself and submit it to Medicare. The cost is typically less than \$100. Charting the numbers from these three tests is especially important prior to starting any new treatment so there’s a benchmark for gauging the effectiveness of the treatment with subsequent test results.”

Assess Your Disease State 2.

...continued

A circulating tumor cell test (CTC) is an advanced blood test that detects cancer cells in Stage 4 prostate cancer. Circulating tumor cells are cancer cells that have broken away from an existing tumor and entered into the bloodstream. The presence of CTCs in the blood provides valuable insights into disease progression. A CTC test used in conjunction with the PSA test allows doctors to more accurately evaluate the effect of treatment on a patient's tumor.

In addition to monitoring blood markers, **you need to know exactly where the cancer is located** in order to treat it. Imaging is a critical part of diagnosis and treatment. One of the recent advancements in imaging is an **MRI scan of lymph nodes** to detect prostate cancer after an injection of Feraheme® (ferumoxytol), a drug that serves as a replacement for Combidex® (ferumoxtran-10), which is no longer available. You're most likely already familiar with some of the imaging techniques such as CT scans, MRI, ProstaScint®, and ultrasound.

Request copies of all imaging test reports for your file. Along with a summary report, **get a copy of the actual test images**. Correctly interpreting the test images dictates the accuracy of the report. You may want to ask your doctor if he reads the images himself and develops the report, or if he has a service read the images for him and generate the report.

Beyond the charts and test results, **pay attention to how you feel**. Are you unusually fatigued? If so, let your doctor know. You may be experiencing anemia caused from the lack of red blood cells. This is common once prostate cancer has metastasized to the bones, which are responsible for producing red blood cells.

If you were exposed to Agent Orange while serving in Vietnam and/or Korea, find out about benefits or compensation you may be entitled to receive. The U.S. Department of Veterans Affairs recognizes prostate cancer as one of 16 diseases caused by this herbicide, which was used for defoliation during the war. (See page 40.)

Pickles



3. Identify Your Treatment Options

Identify your disease state, all possible **paths for progression**, and a **treatment plan** to pursue the most hopeful path. Your decision on the best course of treatment to manage your advancing prostate cancer will be primarily based on conversations with physicians to discuss the results from blood analysis, tissue biopsy analysis, and imaging tests.

**“The purpose
 of life
 is
 life’s purpose.”**

Bill Blair

Before you begin interviewing multiple doctors in your pursuit of medical care for the next phase of treating your prostate cancer, take some time to **evaluate the experiences** you’ve had with your physicians and treatments up to this point. If you’ve consistently done certain things that have worked well to identify doctors and communicate with them, take note of those as some of the things you’ll want to continue to do moving forward. Conversely, if you know that there are things you chalked up to being a learning experience, **leverage that knowledge to be more effective now.**

Questions to Ask Yourself

1. What is my view of doctors?
2. How well do I communicate with them?
3. Has there been any pattern of positive or negative reactions throughout my disease treatment up to this point?
4. Does being empowered to self-manage my treatment seem like a natural approach for me/my personality?
If not, is it reasonable to expect that I can adopt this approach?
If not, can I designate my spouse or a close friend or family member to be my “coach” or the CEO of my medical care?
5. Do I understand my disease status?
6. Who/what am I looking for to help me?
7. What do I want/need?
8. What are my limitations, if any?
9. What criteria will I use to evaluate each physician?
10. How will I monitor my progress?

Identify Your Treatment Options *...continued* 3.



Fred Gersh

“Even though the process can be overwhelming, it’s extremely important to get a second and possibly a third opinion on suggested treatments from physicians who are each in a different specialty discipline. Look for the best doctor who’s open-minded and can provide objective advice rather than being biased to a particular treatment or discipline.

“Find a physician who’s highly regarded to suggest the steps you should be taking next. Understand that the doctor who provides the ‘right’ advice is not always the ‘right’ doctor to do the

treatment. You need to find the expert who may or may not have the best bedside manner. But if he truly is the best, then let his reputation speak for his value.

“I was persistent until I found an excellent oncologist who was willing to work with other physicians. When I decided on radiation and chemo, he helped me find the most highly regarded specialists for those treatments.”

Schedule a time for an initial consultation to speak with each of the doctors you’re considering as additions to your medical team. **Prepare a list of questions** to ask about the approach they would recommend for your treatment, side effects associated with the treatment, and techniques for managing those side effects. **Take someone with you** to your doctor appointment to **catch whatever detailed information you might miss** and to help you process the information afterwards. Keep in mind that **your goal is to find the doctor who has extensive experience** specific to the treatment that you are pursuing.

Although a pleasant bedside manner is nice,
stay objective in your evaluation of a physician.

Keep your focus on his or her technical skills and medical expertise.
How much experience do they have with the exact procedure that you need?
It’s important for you to trust your doctor and have confidence in him or her.

But the best doctor for you isn’t necessarily
the type of person you’d choose as your best friend.

Questions to Ask Your Doctor

1. What do you know from the results of my blood analysis, tissue biopsy analysis, and imaging tests?
2. What do my current PSA, testosterone, and DHT levels tell you about my current treatment? How often do you routinely check each of these levels?
3. What criteria do you use to evaluate your patients and recommend a treatment?
4. Is there any other information that you need or tests you would recommend prior to completing your assessment of my disease and recommendation for my treatment?
5. What primary treatment are you recommending (hormone therapy, radiation therapy, chemotherapy, etc.) and why?
6. To what extent will this treatment be customized to my individual disease state?
7. Do you recommend any supplemental treatment?
8. When do you propose that I start this treatment?
9. What kind of results can I expect from this treatment?
10. How likely is it that I will respond to this treatment?
11. How much time would it take before I know if it's working?
12. What are the specific effects/benefits of the treatment(s)?
13. What are the risks of the treatment(s)?
14. What are the short-term side-effects of the treatment(s)?
15. What are the long-term side-effects of the treatment(s)?
16. How can I best manage the side effects?
17. Does this treatment restrict me from doing anything that's part of my regular daily routine?
18. Is there anything that I need to change in my diet or exercise regimen?
19. How can my loved ones be most helpful to me during this treatment?
20. What specialist is regarded as being the most accomplished with this treatment?
21. What other treatments are available beyond this if it is not effective?
22. Are there clinical trials that may be appropriate that I should consider? If so, what treatment and why do you think it may be helpful? Where can I find information about the clinical trials?
23. Is there another specialist that you can recommend for me to see for a second opinion?

**Be Bold
and
Prepared!**

Identify Your Treatment Options **3.**

...continued

“As a medical oncologist, I knew more about prostate cancer than many patients when I was diagnosed in 1999. Even so, it was still tough for me to make the treatment decisions. I eventually decided on lymph node surgery, radiation therapy, and intermittent hormonal therapy. This required weighing my options, getting my family’s input, and traveling to receive treatment from the prostate cancer specialists who I felt were the premier practitioners in their field. My radiation therapist saved my life at a time when many would not use radiation to treat an aggressive cancer like mine.

I had to do a fair amount of research but think that’s something every man must do for himself. People are naïve if they believe they will receive premium care by simply going to a local urologist at a local facility. In my opinion, that approach is short-sighted and dangerous. Do your homework. Be smart about selecting both your treatment and medical team.”

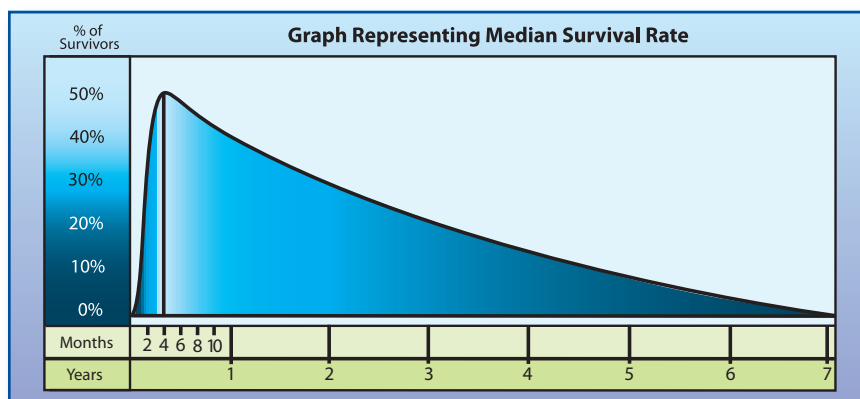


Charles "Snuffy" Myers, MD

In order for you to effectively manage your treatment, **you need to understand the data** that’s generated by each test, what it tells you about your disease state, and how it impacts your treatment. **Ask your doctor** any questions you may have so you fully understand each report.

Median survival rates denote how long patients survive with a disease in general or after a certain treatment. It is the length of time, in months or years, when half the patients are expected to be alive. It

means that the chance of surviving beyond that time is 50 percent and it gives an approximate indication of the survival as well as the prognosis of a group of patients with a cancer. For example, if the median survival of patients with advanced prostate cancer treated with a particular drug is four months, the chance of living beyond four months is 50 percent with some patients living much longer. The graph below illustrates an example of this concept showing a median survival rate of four months with some patients living as long as seven years.



Talk to people who are patients of the physicians you’re considering, and talk to others who’ve worked through the same decision process that you’re facing. Your local Us TOO support group can be an invaluable resource for information, advice, and perspective.

3. Identify Your Treatment Options ...continued



Kay Lowmaster

“If you aren’t already attending an Us TOO support group please consider doing so. There are so many advantages to talking with others to help sort through the ongoing treatment options and decisions that you face. Just knowing you’re not alone in this and that your feelings are normal often lifts the weight of the world off your shoulders.”

“A support group is one of the few places you can openly talk about the challenges that are unique to managing

prostate cancer. Face it—most people around the water cooler are not comfortable listening to a guy talk about issues such as hot flashes or enlarged breasts. Not that you have to talk at all; sometimes it’s helpful to just sit and listen to others. You’ll meet people you can talk with between group meetings.

“Your local support group is a huge resource of ‘best practices’ where you can tap into the collective intelligence of others while sharing your experience and knowledge. Plus, it’s encouraging to see that not only are there many men who are living with advancing prostate cancer, but they are living well and have maintained their quality of life. Putting a face and a name on the courage and strength shown in the battle with prostate cancer is inspirational and motivational.”



Develop and Reassess Your Treatment Plan 4.

After asking the right questions map out your Treatment Plan A and Treatment Plan B. But **always keep looking for new alternatives**—new drugs, clinical trials, regimens. Your needs will change and your treatments will change. Be vigilant, flexible and informed so you're ready when it's time to change course to whatever degree is necessary.

Basically, there are **four types of treatment** for advancing prostate cancer: **hormone management, radiation, immunotherapy, and chemotherapy**. We'll review each briefly. You'll find more detailed information about each through the resources listed at the end of this guide.

HORMONE MANAGEMENT

Testosterone and dihydrotestosterone (DHT) are hormones produced in the testes and adrenal gland that fuel the growth of prostate cancer.

Androgen deprivation therapy, or ADT, uses drugs to block the production or absorption of androgen hormones causing the prostate cancer to shrink or grow more slowly. Ideally, testosterone, DHT, and PSA levels drop to practically zero and replicate the effect of a physical castration, or orchiectomy. Although ADT is often referred to as hormone therapy, **it doesn't involve the use of hormones**.

continued on next page...

Know that all drugs used in hormone therapy can be grouped into three categories:

1. Anti-androgens **block** the interaction of testosterone with cells normally stimulated by testosterone, which includes prostate cancer cells. Examples of anti-androgen drugs include Casodex[®] (bicalutamide), Eulexin[®] (flutamide), and Nilandron[®] (nilutamide).
2. Luteinizing hormones signal the production of testosterone. This process is **shut down** by using LH-RH drugs that include Lupron[®] (leuprolide) and Zoladex[®] (goserelin).
3. The enzyme 5-alpha reductase converts testosterone into dihydrotestosterone, which is five times as potent as testosterone in stimulating prostate cancer cell growth. Inhibitor drugs used to **interrupt this process** include Proscar[®] (finasteride) and Avodart[®] (dutasteride).

With advancing disease, you need to keep assessing, reassessing and revising your treatment plan. That state of flux is normal under the circumstances. Expect to be constantly alternating between testing and planning; always reassessing and reevaluating – always changing.

“Be prepared with Plan A and Plan B. If Plan A fails, switch to Plan B and develop Plan C.”

Bill Blair

4. Develop and Reassess Your Treatment Plan ...continued

HORMONE MANAGEMENT ...continued

If you're on androgen deprivation therapy, your goal is to bring down your testosterone to castrate levels with a reading of less than 20 nanograms per deciliter (20 ng/dl).

Pay close attention to your test results and know that you're not castrate resistant unless your numbers have first dropped to castrate levels. If your physician's told you that you're castrate resistant, challenge the validity of that assessment by looking at past tests to determine if the testosterone was indeed brought down.

At that point when the treatment becomes ineffective and the cancer begins to grow despite the absence of androgens, the disease state of the prostate cancer is called **hormone refractory, androgen independent, or castrate resistant**. The name of the disease state has changed over the past few years; but all three of these designations refer to the same thing.

You can take these drugs through an injection, a pill, a patch or an implant. Pills or injections provide for concentrated elevations of a drug periodically and can be administered at regular or intermittent intervals. A patch allows for the delivery of a consistent dosage over a specified period of time that can be adjusted. An implant delivers consistent dosage for 12 months through a small, flexible cylinder placed under the skin of the upper, inner arm. Talk with your doctor about your options for drug delivery methods to either maintain ongoing ADT or provide for intermittent therapy by alternately starting and stopping treatment.

Androgen deprivation therapy can involve the use of one, two or three drugs simultaneously. Various combinations for second-line therapy (the continuation of ADT after becoming castrate resistant) may also include the off-label use of **ketoconazole**, an anti-fungal agent. The drug has proven to be effective for treatment of elderly men after at least one androgen suppressive treatment with or without chemotherapy. It can be a valuable option to treat patients who are castrate resistant or those who are not candidates for chemotherapy due to therapies for additional concurrent diseases. Although it's not been tested specifically for these applications, some people have found that **high doses of ketoconazole combined with leukine and hydrocortisone can be used for delaying the start of chemotherapy** or extending the off-time from chemotherapy. **Estrogen patches** are also used as another alternative means to stop or counter the production of androgens.

As we go to press with this publication in May 2011, the FDA has just approved the use of Zytiga™ (abiraterone acetate) along with prednisone (a steroid) as second-line therapy for men who have received prior chemotherapy treatment that includes docetaxel. Abiraterone acetate decreases the level of testosterone by targeting a protein necessary for its production.

Pickles



Develop and Reassess Your Treatment Plan

...continued

4.

HORMONE MANAGEMENT ...continued

“My initial PSA of 39 never went to zero after both surgery and radiation. As it began to rise, I asked several experts when I should start ADT and never got a consensus. Some said to start soon while others said to wait. The response that made the most sense was to start ADT when my PSA reached my ‘panic point.’ For me, that point was when my PSA reached the level it was at when I was diagnosed. As soon as I began ADT, my PSA went down like my bank account at a casino. I was told ADT would last for 14 to 24 months.

“The thought of androgen independent prostate cancer scared the Heaven out of me knowing the treatment to follow would be chemotherapy. I decided to do intermittent ADT to keep my cancer dependent on testosterone for as long as possible. When my PSA remained stable at 0.2 and my testosterone went to 20, I went off ADT and watched both my PSA and testosterone go up. It sure felt good to have testosterone in my body again but I knew I would have to go back on ADT again.

“I used the ‘panic point’ approach for eleven years. With each cycle my PSA did not go down as far as the first time, but it went down. I recommend using intermittent ADT for as long as you can to avoid becoming androgen independent. Also, keep an eye on all those nasty side effects of ADT: bone loss, weight gain, hot flashes, loss of libido, high blood pressure, insulin spikes, and ... oh, I almost forgot ... short term memory loss! All of these can be treated so be aware.”

Jim Kiefert

◆

“Jim Kiefert and I have been in regular contact throughout our ADT experiences to compare notes along the way. He and I have a

slightly different approach. However, we’re both convinced that our long-term survival depends upon a combination of good medical help, a positive attitude, considerable sharing of information, and our laughter – even when faced with the serious situation of advancing prostate cancer.

“I, too, was diagnosed with a high PSA of 27, along with a Gleason score of 7 (4+3), and cancer in one lymph node. I had 3D conformal external beam radiation and immediately started ADT 3. I meticulously plotted my PSA, testosterone, and DHT for 10 years, went on a very strict Mediterranean diet low in saturated fat with no red meat, took numerous supplements, and followed a daily exercise program. Unlike Jim, I chose to restart my ADT when my PSA reached 7 rather than my original PSA of 27. After 10 years, my ADT began to fail and it was time for my Plan B, which I had at the ready for when it was needed.

“I’m now on second line hormonal therapy, which involves ketoconazol, hydrocortisone, estrogen patches, and a daily self-injection of Leukine®. My PSA again went to zero but there are considerably more nasty side effects. There are also more details that I must manage, more results to monitor, and it’s more expensive. I have a Plan C ready, if needed.

“Jim and I are now into less proven treatment areas where there are less certain results. Participation in an Us TOO advancing support group like the Us TOO Mets Mavericks and Chicago-area Wellness Place support groups is now especially valuable. In spite of the situation, I’m convinced that with good friends like Jim and new research underway, there is HOPE for the future.”

Russ Gould

4. Develop and Reassess Your Treatment Plan *...continued*

RADIATION

Radiation can target the prostate and specific sites where the cancer has metastasized. It can be used alone or in combination with androgen deprivation therapy, immunotherapy, or chemotherapy.

In the early stages of prostate cancer, radiation therapy may be used instead of surgery, or it may be used after surgery to kill remaining cancer cells. Normal bodily functions keep the prostate in motion. The Calypso “GPS for the Body” system monitors movement of the body and the prostate’s exact location. **Intensity modulated radiation therapy (IMRT), 3D conformal radiation therapy (3DCRT), proton beam therapy (PBT), CyberKnife, and brachytherapy** are all types of radiotherapy that concentrate radiation on specific metastatic cancerous sites to minimize cell damage to surrounding tissue.

It is common for advancing prostate cancer to metastasize to the bones. Although radiation therapy will not eliminate all cancer cells in the bones, it can help relieve bone pain.

External radiation treatment is given to the affected bone or area as a single treatment, or as a series of treatments. It can take several days to several weeks for pain to lessen during which time pain may increase slightly before decreasing.

If several areas of bone are affected and are causing pain, radiation can be administered into the bloodstream through an injection of a liquid radioisotope compound like **strontium 89 (Metastron®)**. Since strontium is very similar in structure to calcium, it is absorbed by the affected areas of bone. It may take up to three weeks to realize pain relief, which can last up to three months. The treatment can shrink the cancer in the bones and delay development of future bone tumors.

IMMUNOTHERAPY

Immunotherapy or biotherapy uses the patient’s own immune system to fight cancer when standard therapies have failed. **The only FDA approved immunotherapy for prostate cancer is Provenge® (sipuleucel-T)**, which is an active cellular immunotherapy. It involves a process designed to fully activate a man's immune cells to better identify prostate cancer cells as abnormal cells in the body. Approximately 95% of prostate cancer cells express an antigen called **prostatic acid phosphates, or PAP**. Provenge® helps a man's immune cells recognize cells that display PAP and attack those cells.

continued on next page...

Hormone Management ... Humor

GRIN #1

Doctor: Well, we better discuss treatment now for your prostate cancer. I recommend hormone therapy.

Man: Are there any side-effects?

Doctor: A few. You will have a loss of libido. You might get some hot flashes. And when lost, you will have an inexplicable urge to ask for directions.

GRIN #2

On hearing that estrogen would take over as testosterone faded from my system, my wife's first question to the doctor was, "Will he finally enjoy shopping with me at the mall?"

Develop and Reassess Your Treatment Plan

...continued

4.

IMMUNOTHERAPY ...continued

The process involves extracting the white blood cells (immune cells) and sending them to a Dendreon Corporation facility where they are activated to program T cells (that belong to a group of white blood cells known as lymphocytes) to destroy prostate cancer cells. The newly activated cells are returned and then infused into the individual three days later. Since the blood cells are from the patient, there's little chance of rejection. The most common side effects are flu-like symptoms that last about 24 hours. This infusion process is repeated three times with two weeks between each infusion.

Provenge[®] was approved by the FDA in April of 2010 after demonstrating safety and a survival benefit of just over four months. The survival benefit of four months was the median. **Some of the men treated with Provenge[®] during the clinical trial benefited more than others and are still alive five years later.**

The clinical trial included men with metastatic castrate resistant prostate cancer, some of whom failed chemotherapy and therefore had exhausted other treatments options. The hope is that Provenge[®], when used on men with a smaller tumor burden and in better health, would result in a much better survival benefit.

“I was fortunate to be enrolled in a clinical trial for Provenge[®]. When my activated immune cells were being infused into me in April 2010 the nurse ran into the room and informed me that Provenge[®] has just been approved by the FDA. I had my immune cells treated three times. Since my treatment, my PSA has stabilized despite the fact that my PSA had been going up while on ADT. Of all the treatments I have had for my prostate cancer, this one had the least side effects.”

Jim Kiefert

CHEMOTHERAPY

Chemotherapy is typically employed **only after all other treatments have failed** to manage advancing prostate cancer. Recent advancements in chemotherapy offer new drugs for extending life with advancing prostate cancer.

Approved by the FDA in 2006, Taxotere[®] (docetaxel) was the first drug that provided **extended survival benefits for castrate resistant patients** and is the most widely used and **most effective chemotherapy option** for advancing prostate cancer. It's administered as a one-hour infusion every three weeks generally over a ten-cycle course and it's possible to see results within the first three treatments. If not, you can try something else at that point and there are **no lasting negative side effects from docetaxel.**

The newest drug available is Jevtana[®] (cabazitaxel), which received FDA approval in 2010 for the **treatment of castrate resistant prostate cancer.** Jevtana[®] in combination with prednisone can be used following or during docetaxel-based treatment.

A common and very painful side effect of chemotherapy is the loss of fingernails and toenails. Some people have found that they don't lose their nails if they apply ice packs or frozen peas to their finger tips and toes during the chemo infusion.

4.

Develop and Reassess Your Treatment Plan

...continued

CHEMOTHERAPY ...continued

“Differentiate between the services of a surgeon and a prostate cancer treatment specialist. Unless your urologist has received additional intense training in urologic oncology, recognize that his expertise is that of a surgeon. He may be a nice guy and you may think that he knows everything about treatment since he’s working with prostate cancer. But realistically there just isn’t any one doctor who knows everything that’s necessary for your comprehensive care throughout all phases of the disease. Managing advancing prostate cancer takes a team of physicians who are specialists.

“Once your treatment includes chemotherapy, you should be under the care of a medical oncologist who specializes in prostate cancer, and is one member of your multi-disciplinary medical team that also includes a urologic oncologist and a radiation oncologist. They should all be consulting and interacting with each other.

“Find each of these prostate cancer oncology specialists before you actually need to see them. This will help make the transition easier when the time comes. Remember to get answers to all of your questions and to never blindly trust your oncologist or any physician with your care. Nobody knows your medical history and your condition better than you. Therefore, you need to steer your treatment. This is your life you’re dealing with here. You have a choice. Control the course of your treatment through choosing the best specialists to help you throughout the course of your disease.”



Shirley Grey

Most chemotherapy treatments involve a combination of several chemo drugs, which is referred to as a drug regimen. Most of the drugs are given intravenously in a cycle every 21 or 28 days. This allows ample time for them to make an impact and allows the body time to recover from **the side effects, which can be substantial.**

Chemo rage is one of the names given to behavioral and emotional mood changes or distress that may occur as a side effect of chemotherapy. It’s characterized by feeling edgy or restless or experiencing outbursts of anger, extreme personality changes, or depression. Be aware of these conditions, which can cause you to feel like you’re emotionally out of control. They can be managed with prescription medications.

Another side effect of chemo is known as **chemo brain or brain fog**. Symptoms of this condition can include a lapse in short-term memory for words, events, and mathematical computations; and difficulty performing motor skills or maintaining concentration on a specific task.

continued on next page...

Develop and Reassess Your Treatment Plan

...continued

4.

CHEMOTHERAPY ...continued

“I’m a warrior who’s battled prostate cancer for 22 years. I’ve been managing my advancing disease with chemotherapy since September of 2009 with 23 infusions of Taxotere® to date and more to follow—one every three or four weeks. This is my latest weapon in an arsenal that’s also included a radical prostatectomy, external beam radiation, and hormonal therapy. Nobody wants to be on chemotherapy; and sure, I have my down days every now and then. But overall, I’m positive and hopeful. My attitude has been and continues to be my most effective weapon to combat my disease. I choose to be positive and passionate about life. I want to be there to enjoy future milestone events with my wife, children and grandchildren. I’m hopeful about the new drugs and treatments that are down the road to help me effectively manage my disease moving forward. Talk is cheap. It’s easy to say that one must have a positive attitude. It’s really hard to live it. But you must. Just take one day at a time and do the best you can. Keep on keeping on.” Fred Gersh

Chemotherapy often affects how food tastes. While the chemo drugs are attacking the cancer cells, they are also affecting the taste buds or clusters of bulbous nerve endings on the tongue and in the lining of the mouth that provides the sense of taste.

Some of the short-term actions a chemo patient may take include:

- Using plastic eating utensils to avoid the metallic taste
- Sucking ice chips, eating ice cream, sorbet, sherbet
 - Sucking on sugar-free flavored lozenges/candies (peppermint, lemon, ginger)
 - Chewing fennel and cardamom seeds
- Using a straw for liquids, and drinking smoothies

Exercise good oral hygiene by brushing your teeth and tongue before and after meals, and rinsing regularly before and after meals with a teaspoon of baking soda in eight ounces of water.

Some cookbooks feature recipes specifically geared toward the cancer patient and are designed to help alleviate many of the side effects that accompany chemo such as nausea, fatigue caused by lowered red blood cell counts (anemia), diarrhea, and constipation.

The greatly reduced sense of taste in food often results in people not eating as much as they should and thereby losing weight. For some people eating is more enjoyable if they’re around other people. They tend to eat more. If this holds true for you, make sure you don’t eat alone. (See page 39 for link to article on Chemotherapy and Taste Issues.)

4. Develop and Reassess Your Treatment Plan ...continued

CONSIDER CLINICAL TRIALS

**“Feel in control.
Decide between
a struggle
and
an adventure.”**

Bill Blair

Prior to Food and Drug Administration (FDA) approval of any prostate cancer treatment, drug, or therapeutics, clinical trials are conducted to answer specific questions about new treatments, test new ways of using established treatments, and demonstrate safety and efficacy. Clinical trials are often conducted by pharmaceutical companies as well as researchers at major medical centers. Each study enrolls patients with certain types and stages of cancer and certain health status. **Patients participating in a clinical trial typically incur no cost over and above standard care.** Benefits to participation include gaining access during and after the clinical trial to new treatments that are not yet available to the general population, and contributing to medical research that may result in the advancement of prostate cancer treatments to help other men down the line.

Phase I trials are designed to **measure safety** and **Phase II trials** determine the **appropriate dosage**. Once the drug has passed Phase I and II, it goes to **Phase III** to determine its **effectiveness**, which involves one group of participants receiving a placebo and another group receiving the treatment.

“Your doctor may not be involved in clinical trials so YOU need to be active. Check www.clinicaltrials.gov and search for your conditions. It will give you all the information you need. Also, talk to your support group members about any clinical trials that may be appropriate for you.

“Realize that clinical trials are only open for a limited window of time. So to some degree, it’s the luck of the draw to find a drug that may help you when you need it. Once you’re in a clinical trial, you have the option of dropping out at any time.

“Be involved and informed. Read, learn and be prepared to ask questions. I had to call around to get information on clinical trials. Once again, nobody’s going to do this for you. Is your life worth it? Make it happen.”

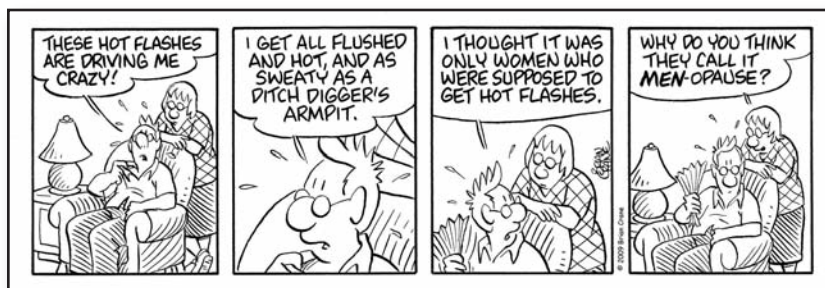
Jim Kiefert

Some drugs that are effective in treating advancing prostate cancer are **used off-label**. These are drugs that have received FDA approval and have proven to be effective for treating a disease other than advancing prostate cancer. Become aware of the off-label drugs that have helped others manage their advancing prostate cancer. Always be diligent in your quest for new information, new resources, and new people to talk with or add to your team. Your treatment plan should be a working document that you reassess and update as often as you find necessary. It should always align with your disease state and include new technologies and the latest treatment opportunities available to you.

Anticipate Side Effects and Know How to Manage Them **5.**

| TREATMENT | OVERVIEW | SOME COMMON SIDE EFFECTS |
|------------------------------------|---|---|
| Hormone Therapy | Use hormones to minimize presence of androgens, the “fertilizer” for prostate cancer growth. | Erectile dysfunction (ED), loss of libido, menopause-like symptoms (hot flashes), gynecomastia (enlarged breasts), bone loss, insulin sensitivity |
| Chemotherapy | Use drugs to stop cancer cell growth; targets cells that grow/divide quickly, which can include cancer cells metastasized to bones. | Hair loss, fragile bones, nausea, constipation, vomiting, diarrhea, nervous system disorders (headache, confusion, depression) |
| Radiation | Use ionizing radiation to kill cancer cells; introduced externally or internally as implanted seeds. | ED, frequent urination with burning sensation, blood in urine/stool, diarrhea, rectal bleeding or pain, discomfort during bowel movement |
| Biotherapy or Immunotherapy | Use agents to manipulate the body’s immune system; program it to kill cancer cells. | Possible fever |

Pickles



“Out of crisis comes opportunity.”

Bill Blair

MAINTAIN BONE HEALTH

Your bones may be affected by prostate cancer in two ways. Advanced prostate cancer can metastasize to the bones. Bone loss can result as a side effect from treatments and medications taken to manage prostate cancer. **Androgen deprivation therapy** can be used to control the spread of cancer to the bones. Drugs including Xgeva[®] (denosumab) and Zometa[®] (zoledronic acid) help maintain bone health to avoid fractures.

Xgeva[®] received FDA approval in November of 2010 for the prevention of skeletal-related events (SREs) in patients with bone metastases from solid tumors. Compared to Zometa[®], it’s more convenient since it’s delivered through an injection in the belly rather than an infusion and there’s no need for dose adjustments. Plus, it’s not toxic to the kidney so renal monitoring isn’t necessary. Patients taking Xgeva[®] should also take a calcium supplement to avoid hypocalcaemia and Vitamin D to help the body absorb the calcium.

continued on next page...

5. Anticipate Side Effects and Know How to Manage Them

...continued

MAINTAIN BONE HEALTH ...continued

Optimizing bone health largely depends on managing your diet and exercise. Get as much calcium as possible with green vegetables and defatted soy products. Take a calcium supplement, if necessary, to get at least 1200 mg of calcium per day. Don't eat too much protein daily since it can prevent your body from retaining the calcium. Cut back on salt, which reduces your body's ability to use the calcium; and get enough Vitamin D so your body can process the calcium.

“Include about 30 minutes of weight-bearing exercise every day to help build your bone structure. Get a bone mineral density test to gauge your current bone health and to serve as a benchmark for future tests throughout your treatment regimen. The DEXA scan is the most common bone mineral density test. Some doctors may suggest that a quantitative computed tomography, or QCT, is more accurate.” Russ Gould

“I've had bone mets since 2003. You need to know that there are people like me who've survived many years with bone metastasis and others who similarly are living with prostate cancer that has metastasized to lymph nodes. I lead a very active lifestyle that includes my passion for riding my motorcycle, hiking and boating. I'm also very dedicated to exercise—especially resistance exercise. I may have prostate cancer but prostate cancer doesn't have me. It doesn't define me.” Jim Kiefert

MINIMIZE PAIN

Being tough serves a man well in many circumstances throughout his life. However, it's not necessary or appropriate to try to ride out the pain that can be associated with the prostate cancer itself and some of the treatments for the disease. Acknowledge your pain and the amount of pain you choose to endure relative to the negative impact that it can have on your quality of life.

Recognize that the effects of your pain extend beyond you to those around you who love you and would do anything possible to help you. If you chose to be in unnecessary pain, they are required to become helpless observers of your suffering. **Talk with your doctor about pain management.** After defining the extent and source of your pain, a customized regimen can be developed which can include medications, physical therapy, and acupuncture.

Anticipate Side Effects and Know How to Manage Them **5.**

...continued

MANAGE INCONTINENCE

You may have already dealt with urinary incontinence as a common side effect from a prostatectomy. In that situation, it's often only temporary while the body recovers from the surgery and Kegal exercises help build muscles in the pelvic floor.

When associated with advancing disease, incontinence most often occurs after having radiation treatment. Absorbent products, a penile compression device (penile clamp), and condom catheter devices are common non-surgical responses to the problem. Additionally, a device referred to as a "male sling" can be implanted to support the muscles around the urethra through a minimally-invasive procedure to correct mild to moderate stress urinary incontinence. Another option is to surgically implant an artificial urinary sphincter, which uses fluid contained in the closed system to relax or constrict the urethra thereby maintaining continence and permitting voiding to empty the bladder.

“Urinary incontinence is often discussed in our Mets Mavericks support group for guys with advancing prostate cancer. Those who’ve dealt with it can all relate to the major negative impact it can have on their daily routine, self-confidence, and overall quality of life. Unlike many other symptoms and treatment side effects, urinary incontinence is more invasive and intrusive because it’s a constant reminder of living with the disease.

“Every man wants to feel in control of his life. It can be extremely frustrating to not be able to control one of the most basic bodily functions. A guy shouldn’t have to be afraid to laugh or sneeze; or wear the wrong color pants. This lack of self-confidence can prevent him from keeping a normal schedule resulting in a less active lifestyle, which can lead to muscle loss and weight gain—all potentially contributing to an emotional downward spiral. But much can be done to manage or restore urinary control, regain confidence and maximize quality of life.

“All of this has an enormous impact on a guy’s ability to maintain a positive attitude. And a positive attitude is the single biggest weapon you have for effectively managing your advancing disease.”

Russ Gould

5. Anticipate Side Effects and Know How to Manage Them

...continued

MAINTAIN INTIMACY

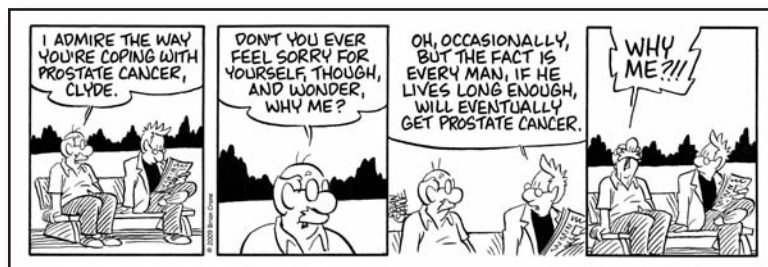
Recognize that intimacy and sex can occur at the same time but can also be mutually exclusive. There are ways to show and share intimacy that do not require medications or devices. Intimacy is about a physical closeness that's an outward expression of the love between two people. It's tender touching, caressing, kissing, hugging each other, looking deeply into each other's eyes while listening to soft music, or just holding hands. Speaking is optional. Reach back in your memory to when you were dating. Get in the back seat of the car again (or even just the front seat...) and imagine the possibilities! You have everything you need for intimacy; go for it!

You may not be interested in having sex. A loss of libido is a common side effect from androgen deprivation therapy. But for many people, a healthy sex life is an integral part of their overall happiness. If you're looking to accentuate intimacy with sex, there may be a few hurdles to clear. **One of the more common side effects of prostate cancer treatment is erectile dysfunction, or ED.** But there are plenty of ED treatment options to help perk you up and recapture an active sex life.

Medications such as Viagra® (sildenafil), Cialis® (tadalafil), or Levitra® (vardenafil) cause the blood vessels and tissues of the penis to relax and dilate allowing blood to rush in and an erection to occur. The same effect can be achieved by introducing the drug, alprostadil, directly into the penis through injections or through a suppository pellet that's inserted into the opening at the tip of the penis through a plastic tube. This process is commonly known as MUSE, or medicated urethral system for erection.

Another option to treat ED is a penile prosthesis or penile implant. Bendable rods can be surgically implanted within the erection chambers of the penis resulting in the penis being permanently in a semi-rigid state. There's also an inflatable prosthesis that consists of a squeeze-activated pump and reservoir of fluid implanted in the scrotum. A valve regulates the fluid entering or exiting tubing inside cylinders that are surgically implanted in the erection chambers of the penis.

Pickles



Anticipate Side Effects and Know How to Manage Them **5.**

...continued



Jerry Hardy

“You don’t have to choose between surviving prostate cancer and remaining sexually intimate. There are many treatment options available for ED. It took my wife, Jo Ann, and I three years to find the perfect solution for my impotence. The pills didn’t work. Neither did the injections or pellets. After asking a lot of questions and learning more about penile implants, I decided to have the surgery for an inflatable prosthesis. That was back in 2004 and since then we’ve lived happily ever after!

“Whenever Jo Ann and I talk with couples seeking help for ED, we always encourage them to become educated about all of the options, talk to support group members who’ve tried the treatments, and find a urologist experienced in treating ED. Don’t be afraid to ‘doctor shop’ to find the physician who’s best for you and the procedure you need. Be empowered and be fearless in getting help to achieve the level of sexuality that you want and deserve. Know that an active and healthy sex life doesn’t have to be a casualty of your prostate cancer treatment.”

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

We’re all struck by the opportunity and richness of birth. Leaving our earthly life also offers meaningful interactions. But most people are uncomfortable discussing death, which stifles free and open communication. Too often loved ones think that the patient can’t handle the prospect of dying; or doesn’t know they’re dying—which is never the case. And the patient thinks the family can’t handle the conversation about death. Being aware of impending death can be another opportunity for empowerment by recognizing those aspects of death that can we can manage.

continued on next page...

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

...continued

“I’m a very pragmatic person and realize that regardless of having advanced prostate cancer, at some point everyone is going to die. Whenever possible, it makes sense for a person to have an end-of-life plan. I owe it to my wife and family to plan for my death so when the time comes, the transition into their life without me in it will be as painless as it can be. It’s just one more way that I can demonstrate the love that I have for them. I have updated my will and health directive; and shared that information with my family. I have a total sense of calm now that I have everything in order. Not surprising, you won’t hear much about end-of-life information from your physician. Docs tend to be hard-wired to save lives and maintain positive attitudes to impact patients’ recovery from diseases. But not addressing the subject can be a disservice, since death is a natural part of the life cycle that everyone will have to face at some point in time.”

Jim Kiefert

Palliative care is appropriate for anyone with a serious, complex illness such as advancing prostate cancer. Hospice care is palliative care that is provided to a patient with life expectancy of six months or less. It includes disease symptom relief, pain management, psychological care, and spiritual care within a support system to help the individual live as fully as possible. Hospice does not include any type of active treatment to lengthen or shorten life, but focuses on the quality of life for the amount time the patient has remaining. Medicare will cover the cost of hospice.

The benefits of hospice extend beyond the patient to provide help for the family. Care-givers can take periodic breaks knowing that hospice workers are attending to their loved one. Hospice services also offer the patient’s family an opportunity for dialogue, counseling, and support group meetings to work through bereavement for up to 12 months after a patient passes away.

In addition to preparing legal paperwork including durable power of attorney, a living will, and a conventional will, you may want to communicate your personal, emotional, and spiritual wishes. **“Five Wishes” from Aging with Dignity is an excellent document** that you can use to manage your health care decisions, medical care, comfort, treatment, and personal intentions. It’s included in the resources section of this guide on page 40, and can be an effective tool in starting the conversation that’s best to have sooner rather than later.

If your physician doesn’t bring up the topic of end-of-life planning, you have the option to do so. **Remind your physician that as of January 1, 2011 Medicare will reimburse physicians for discussions about end-of-life planning with patients who want it.** Medicare will pay for elective annual discussions about end-of-life plans, which can be used to prepare an advance directive stating what treatments a patient does and does not want.

Empower Yourself Daily through Diet, Exercise, Spirituality and Humor **7.**

Having advancing prostate cancer requires you to make a lot of changes and some sacrifices in how you live your life each day. It's helpful if you understand not only what you need to do, but also a few examples of why it makes sense to do it. You know that an **effective exercise routine** maintains your bone health and builds muscle. But did you know that it also **releases endorphins** into your brain resulting in a more positive mental state? We've talked about infusing a bit of humor into your daily life. Did you realize that **laughter** reduces the level of stress hormones while increasing the level of health-enhancing hormones like **endorphins** and the number of **antibody-producing blood cells**? Similarly, many people don't recognize stress as being a contributing factor to ED. Stress produces increased levels of adrenaline, which inhibit an erection.

There are a lot of prostate-healthy diets out there and by this point you've most likely developed a diet that works for you. Certain types of foods must be avoided: primarily red meat containing arachidonic acid, dairy products, and trans-fatty acids. Pattern your lifestyle and eating habits around the Mediterranean diet, which includes fruits, vegetables, beans and legumes; an abundance of bread, pasta, rice, and other grain foods, especially whole grains; nuts and peanuts; extra virgin olive oil; fish, poultry, cheese and yogurt; and moderate amounts of wine.

continued on next page...

“Besides the right diet, exercise is critical regardless of your disease state. Even though hormone therapy eliminates testosterone, it is possible to maintain adequate muscle mass without testosterone and maintain bone health while on androgen deprivation therapy. Find an exercise routine that works for you and is appropriate to the extent that you can participate. Remember that doing something is better than doing nothing. Rather than focus on limitations, leverage opportunities. Regardless of your physical limitations, there's almost always some type of exercise that you can do that will help make you feel stronger and better.”

Russ Gould

7. Empower Yourself Daily through Diet, Exercise, Spirituality and Humor

...continued

Get in an exercise group or find an exercise regimen that you can do on your own. Try to get at least 30 minutes of low-impact, weight-bearing exercise every other day. Walking is another good option. But if that's not practical or possible for you, then start out with what you can do now and increase your activity as you move forward. Talk to other men battling advancing prostate cancer and find out what works for them.

In addition to diet and exercise, **spirituality** plays an integral role in a comprehensive wellness plan. Spirituality can include meditation, communal with nature, counseling others, individual or group prayer, or other religious practices. Spirituality **can decrease depression and anxiety thereby increasing the quality of life**. Establishing a connection between ourselves and a greater power helps add perspective to our lives and hope in the battle with advancing prostate cancer.



Paul F. Schellhammer, MD

“My perspective is somewhat unique since I am both a urologist and a prostate cancer patient. I had a prostatectomy in 2000 followed by radiation and androgen deprivation therapy. In spite of my familiarity with the disease and its management, I was humbled by the fear that I felt when facing my diagnosis with questions about survival and potential suffering, along with concerns about incontinence and impotence.”

“The cancer diagnosis is now personal rather than just hypothetical. Even with my expertise in this medical specialty, decisions are still tough and often unclear for me as I consider my emotions and those of the patient against objective medical information knowing that there is no straight and clear path to follow. But I think having prostate cancer has grounded me personally and professionally.”

“I paraphrase my fellow physician and fellow cancer patient, Dr. Wendy Harpham, who eloquently stated, ‘Cancer has not made my life uncertain. But it has exposed me to the uncertainties of life. When I lessen my concerns and anxiety about tomorrow and appreciate the moment, I have found today in a way that was never before possible.’”

Move Forward

We hope that you've found this guide helpful to empower you to more effectively self-manage your treatment for advancing prostate cancer with practical information and realistic action steps. It's been designed to serve as a starting point with tools and insight to help you manage the disease and maintain your quality of life. We invite you to refer to the list of various resources that follow for more detailed information, talk with your doctor, and attend an Us TOO support group meeting to benefit from the collective knowledge of others through peer-to-peer support.

In addition to Us TOO, become familiar with the other non-profit prostate cancer organizations which are listed as resources. We are all part of an incredible coalition of thousands of people working together to help men and their loved ones in their fight against advancing prostate cancer.

**“Serendipity
is just around the corner.
But you have to
recognize it.”**

Bill Blair

Fight Back and Give Back

We encourage you to consider becoming a warrior whose battle with advancing prostate cancer extends beyond the impact that the disease has on you personally and its potential impact on your male offspring who are more prone to developing prostate cancer. We invite you to consider combining your personal struggle with that of others who are fighting the same battle and form an army with a collective voice that has much more power than the sum of each individual.

Get Involved

There are two million men in the U.S. who are living with prostate cancer. Although not intended, you are now a member of a select group of those men who are living with advancing prostate cancer. Thrust into being a member of a club that nobody ever wanted to join, this group sometimes refers to itself as “the reluctant brotherhood.” But a brotherhood it is nonetheless. Embrace this community of men who are open to helping others by sharing the knowledge they’ve gained from their personal experience with advancing prostate cancer.

Make a Difference

- If you’re already attending a support group, take a more active role.
- If you’re not attending a local support group, GO.
- If there’s not a support group in your local area, get one started.
- Log onto www.ustoo.org and participate in the online discussion groups such as the Us TOO Inspire Community, Prostate Pointers, and My Prostate Cancer Roadmap.
- Participate in an existing fundraising walk for prostate cancer; or start one in your community.
- Organize a *Pints for Prostates* beer tasting fundraising event.
- Consider being a consumer reviewer for prostate cancer research and clinical trials.
- Recognize September as Prostate Cancer Awareness month by contacting landmark buildings in your area and arranging to have them lit with blue flood lights in the evening.
- Get informed and connected to policy developments and speak up as an advocate in your local community to increase awareness for prostate cancer.
- Make your voice heard for government funded research for prostate cancer.
- Increase prostate cancer awareness through a community presentation and conversations with other men at area clubs or organizations such as your local VFW, Chamber of Commerce, or place of worship.
- Reach out to the African American community to encourage annual testing for prostate cancer starting at age 40 since African American men have a prostate cancer incidence rate that’s sixty percent higher than that of white males, and a mortality rate that’s more than double that of white males.



**It's about friendship;
one man reaching out
to help another.**

There is still much to do but we are making great progress. Today we have more treatment options to effectively manage advancing prostate cancer than we have ever had before; and we know that tomorrow there will be even more.



**There
is
Hope!**

The contents of this brochure is available online at www.ustoo.org/principlesbrochure

Resources

p. 10 **CHART YOUR DISEASE DATA**

- & p. 42
- **Medical Smart Chart for graphing tests/results:** www.pcref.org/sample_graph2.php
 - **Access for you to personalize Medical Smart Chart:** www.pcref.org/medsmartchart.php

p. 13 **ASSESS YOUR DISEASE STATE**

- **Us TOO advanced disease web pages:** www.ustoo.org/ADK
- **The Us TOO Inspire Online Discussion Community:**
<http://ustoo.inspire.com> provides online peer-to-peer support and discussions specific to advancing prostate cancer to connect patients, families, friends, caregivers and health professionals for health and wellness support.
- **Prostate Pointers:** www.ustoo.org/Prostate_Pointers.asp features 14 focused & moderated email discussion lists.
- **My Prostate Cancer Roadmap:** www.myprostatecancerroadmap.com is an educational web site that provides resources and information specific to advanced prostate cancer patients and those who love them.
- **Shirley Grey's "Ten Things I Learned While Loving in Sickness and in Health:"**
www.myprostatecancerroadmap.com/take-the-journey/relationship-ten-things-i-learned
- **CancerCare: What's New on the Horizon – Treatment Choices for Men Living with Advanced Prostate Cancer:**
www.cancercare.org/pdf/booklets/ccc_prostate_advanced.pdf
- **CancerCare: Living with Metastatic Prostate Cancer:** www.cancercare.org/pdf/booklets/ccc_mprostate.pdf
- **Email addresses of Us TOO peer support team members:** See page 6.
- **Ask Dr. Barken Call-In Show:** www.pcref.org/call_in_show.php

p. 20 **DEVELOP AND REASSESS YOUR TREATMENT PLAN**

- **Treatment Options:** www.ustoo.org/Treatment_Options.asp
- **Find Us TOO Support Groups:** http://www.ustoo.org/Chapter_NearYou.asp?country1=United%20States
- **Monthly prostate cancer resource from Charles "Snuffy" Myers, MD: Prostate Forum:**
www.prostateforum.com/index.html
- **Prostate cancer videos from Charles "Snuffy" Myers, MD:** <http://snuffymyers.blogspot.com/>
- **Personal perspective on treatment from Paul F. Schellhammer, MD:**
www.foundationforurologicalresearch.com/downloads/My%20Side.pdf
- **"Views from the Other Side: Personal Reflections About Prostate Cancer from Two Urological Oncologists" – Paul H. Lange, MD, FACS and Paul F. Schellhammer, MD, FACS:**
www.foundationforurologicalresearch.com/downloads/ViewsFromTheOtherSide.pdf
- **Prostate cancer videos from Gerald Chodak, MD:** www.prostatevideos.com/
- **Malecare Advanced Prostate Cancer Program Blog:** <http://advancedprostatecancer.net/>
- **Malecare Advanced Prostate Cancer Program:** <http://malecare.org/advanced-prostate-cancer-program/>

p. 28 **ANTICIPATE SIDE EFFECTS AND KNOW HOW TO MANAGE THEM**

- **Post-Treatment Issues:** www.ustoo.org/post_treatment_issues.asp
- **Special Supplement: "Chemotherapy and Taste Issues,"** www.ustoo.org/ChemoSideEffects
- **Agent Orange Compensation:** www.vba.va.gov/bln/21/benefits/herbicide/aono3.htm
- **The National Association for Incontinence:** www.nafc.org
- **The Simon Foundation for Continence:** www.simonfoundation.org
- **National Pain Foundation – Cancer Pain:** www.nationalpainfoundation.org/cat/8/cancer-pain

Resources

...continued

RECOGNIZE THE EVENTUAL NEED FOR AN END-OF-LIFE PLAN

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- **Five Wishes (End-of-Life):** www.agingwithdignity.org/catalog/
- **Advanced Cancer Care Planning from American Society of Clinical Oncology:** www.cancer.net/patient/Coping/Advanced+Cancer+Care+Planning
- **Hospice Care:** www.helpguide.org/elder/hospice_care.htm

EMPOWER YOURSELF DAILY THROUGH DIET, EXERCISE, SPIRITUALITY AND HUMOR

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- **Nutrition:** www.cancer.gov/cancertopics/coping/eatinghints/page1
and: www.ustoo.org/post_treatment_issues.asp#LiveHealthy
- **The Cancer Project** – promotes cancer prevention and survival with nutrition www.cancerproject.org

ADVOCACY AND AWARENESS OPPORTUNITIES

- **Pints for Prostates:** awareness/fundraising events, www.pintsforprostates.org
- **Zero – The Project to End Prostate Cancer:** www.zerocancer.org
- **Women Against Prostate Cancer:** www.womenagainstoprostatecancer.org

PROSTATE CANCER NON-PROFITS

- **Us TOO International Prostate Cancer Education & Support Network:** www.ustoo.org
 - **Prostate Cancer Research Institute:** www.prostate-cancer.org/pcricms/
 - **Prostate Conditions Education Council:** www.prostateconditions.org/
 - **Men’s Health Network:** www.menshealthnetwork.org
 - **Prostate Health Education Network (PHEN):** www.prostatehealthed.org/
 - **The “New” Prostate Cancer Infolink:** <http://prostatecancerinfolink.net/>
- **American Cancer Society Man to Man:** www.cancer.org/Treatment/SupportProgramsServices/MantoMan/index
 - **National Cancer Institute – Prostate Cancer:** <http://www.cancer.gov/cancertopics/types/prostate>
 - **National Alliance of State Prostate Cancer Coalitions:** www.nasppc.org

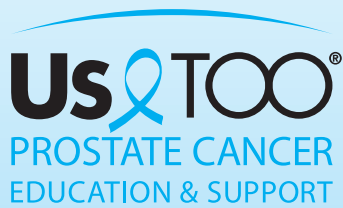
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DISCLAIMER

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 health care provider. All matters pertaining to your health should be supervised by a health care 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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www.ustoo.org



**“To know
the road ahead
ask those
coming back.”**

Chinese Proverb

OUR MISSION

*Be the leading
prostate cancer organization
helping men and their families
make informed decisions
about prostate cancer
detection and treatment
through
support, education and advocacy.*



*Made possible through charitable contributions from
Novartis Oncology, AstraZeneca, Endo Pharmaceuticals,
Veridex, Ferring Pharmaceuticals, GTX, Inc. and people like you!*

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