What Now?

Hope and Options When Experiencing a Rising PSA, A Recurrence of Prostate Cancer, Or When Prostate Cancer is Not Responding to Treatment

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Someone to talk to... who understands
5003 Fairview Avenue, Downers Grove, IL 60515
Support Hotline: 800-808-7866
www.usto.org

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Us TOO
PROSTATE CANCER EDUCATION & SUPPORT
Us TOO International Prostate Cancer Education & Support Network

Someone to talk to…
who understands
What now?

You or your loved one underwent a course of treatment, or selected watchful waiting, in response to a prostate cancer diagnosis, in hopes of:

- a cure
- preventing the spread of disease
- eliminating symptoms in later stages
- slowing the rate of the cancer’s growth
- and/or extending life.

Now, your PSA is rising, or you just learned that the prostate cancer it is not responding to treatment, or perhaps it has returned and even spread.

What now?

This can be a highly emotional time for you and your loved ones. You may feel angry, sad, afraid and frustrated. You also may have many pressing questions, such as:

- Why isn’t the treatment working?
- What does this mean?
- What options do I have?
- Where can I turn for support?

In the face of this new or continuing pressing challenge, it is vitally important to be actively involved in your treatment and care. Partner with your doctor. You are your best advocate. You are the key ingredient in your vitality, quality of life and prognosis. You are not alone.

Most importantly, know that you have options. The purpose of this booklet is to provide information for you to discuss with your doctor and consider as you make decisions.

There are options. There is hope. You are not alone.
In this booklet you will find information and ideas to consider as you make decisions. If you have not yet been actively involved in your care, it is time to move from passive patient to active participant. If you have been actively involved in your care, keep up the good work!

Work closely with your doctor as you consider your options. Your doctor is your partner, but you are your best advocate. Maintain close contact with family and friends through this phase of treatment. Those who have a positive attitude and are actively involved in their lives live well... and longer.

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Questions for your doctor...

The following is a list of questions to ask the doctor if you have experienced a relapse. Ask a friend or loved one to accompany you to your appointment and take notes. It may be worthwhile to audio record your conversation with your doctor so that you can review the answers to each question and be able to make informed decisions about treatment options.

Questions:

- Has the cancer spread and if so, how far?
- What are the treatment options?
- 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 are recommending?
- Where can I find out more about these treatment options?
- 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?
- What can you tell me about new experimental treatment options?
- Should I consider participating in a clinical trial?

Additional resources:

1. Us TOO International Prostate Cancer Education and Support Network
   www.ustoo.org/Experienced_Relapse.asp#QUESTIONS
2. Physician-to-Patient
   www.prostatepointers.org/p2p/
3. Cancer MBA
   http://cancermba.com/content/basic_terms/relapse.html
Getting a second opinion and knowing the score…

Your PSA is rising... Or the cancer has returned. Perhaps it is not responding to treatment. But how much do you really know about what is happening within your body? With your initial diagnosis, your doctor used a number of tools and tests to choose the most appropriate treatment option, weighing the risks of side effects and the probability of successfully treating the cancer. This is also true when you experience a recurrence or the cancer is not responding to treatment.

Reassessment, reassessment, reassessment… This is the mantra for this phase of your journey. You and your doctor should take into consideration the treatment, or course of action, you already received and your overall health. In addition, it is critical for you and your doctor to know the following things before making treatment decisions:

- Is the cancer localized?
- Has the cancer spread beyond the prostate?
- Are the bones impacted?
- Does an elevated PSA reading really mean a cancer recurrence or is this simply a ‘bump’ common after brachytherapy?
- What is my PSA reading telling me?

This section provides information about valuable medical tests, such as diagnostic imaging and bio-chemical tests that can provide answers to these important questions. This section also provides valuable information about important aspects of PSA testing. With this information, you and your doctor can work together to make informed decisions that are most appropriate for you.
Reassessment tools

Diagnostic Imaging

Spectroscopic MRI: Magnetic resonance spectroscopy measures the amount of the prostatic metabolites (substance metabolized in the prostate) called choline and citrate. When cancer is present, choline levels are increased and citrate levels are decreased. This information can be used to localize tumors and assess tumor aggressiveness, and has the potential to predict prognosis more accurately.

Sources:
2. Journal of urology - Hricak, Hedrig; Department of Radiology; University of California, San Francisco; San Francisco, California

PET Scan (also called PET Imaging) – Positron Emission Tomography

A computerized image of the chemical change activity that take place in the body tissues used to determine the presence of disease. This test detects radiation from the emission of positrons. Positrons are tiny particles emitted from a radioactive substance administered to the patient.

The PET Scan not only provides information on the metabolic activity of the cancer but can also locate tumors. The value of a PET scan is enhanced when it is part of a larger diagnostic work-up. This often entails comparison of the PET scan with other imaging studies, such as CT or MRI.

Sources:
1. www.ohiohealth.com/healthreference
3. www.radiologyinfo.org/content/petomography.htm

Photo of PET Scan equipment in use found at:
http://www.phoenix5.org/glossary/positron_emission_tomography.html
**Diagnostic Imaging** (continued)

**Combidex:** Studies indicated tiny iron particles dramatically increase the ability of MRI’s to detect whether prostate cancer has spread to other parts of the body. The iron particles are an imaging agent called Combidex that is injected into a patient’s bloodstream before having an MRI. With current technology, lymph nodes appear bright on an MRI and physicians measure the size to determine if they are cancerous. According to one study, Combidex improved the detection of cancerous nodes using MRI technology. The findings fuel hopes for a less invasive and more accurate way to detect the spread of prostate cancer.

Combidex received an approval letter, subject to certain conditions, from the U.S. Food and Drug Administration (FDA) in March 2005. Advanced Magnetics, the company that manufactures Combidex, is currently evaluating available data from ongoing studies, including studies from Guerbet, their European partner, to determine if these studies will satisfy the concerns raised by the FDA in the March 2005 approvable letter. Advanced Magnetics hopes to be able to submit a complete response, which will include new data, to the FDA by the end of calendar 2006. Combidex is now available in parts of Europe.

Source:
* Advanced Magnetics, Investor Relations
* Boston Globe. Entire article found at: ww.ustoo.com/PDFs/HotSheets/HotSheet072003.pdf

**Bone Scan:** A bone scan looks for abnormalities in the bones. You may hear it called a radionuclide scan or scintigraphy, different than simple peripheral or central Bone Mineral Density (BMD) testing. A radionuclide bone scan can look at a particular joint or bone. In cancer diagnosis, it is more usual to scan the whole body. The scan involves one injection, but apart from that, it is painless. The bone scan is quite sensitive for demonstrating metastatic disease in the skeleton.

The bone scan uses a large camera called a 'gamma camera'. This is a camera that picks up radioactivity from a radioactive substance called a radionuclide injected into your blood stream. The radionuclide travels through the blood and collects in your bones. More of it tends to collect in areas where there is a lot of activity in the bone. 'Activity' means the bone is breaking down, or repairing itself. These areas of activity are picked out by the camera. They are commonly called 'hot spots'.

Source:
www.cancerhelp.org.uk/help/default.asp?page=151
www.mayoclinic.com/invoke.cfm?id=CA00020

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**Resource:**

**Us TOO Prostate Cancer HotSheet:**

A monthly newsletter, the HotSheet, highlights the latest in treatment strategies as well as emerging treatments.

The HotSheet is distributed free at Us TOO chapter support group meetings, and is available in PDF on the Us TOO website. (www.ustoo.org)

HotSheet subscriptions are available by calling (630) 795-1002. Or visit www.ustoo.org to download and print a subscription order form.

HotSheets supported by a charitable contribution from AstraZeneca.
Diagnostic Imaging (continued)

ProstaScint®: ProstaScint® is an imaging agent and is used for:
- newly diagnosed patients
- restaging of post-prostatectomy and post-radiation therapy patients with a rising PSA level
- restaging patients with hormone resistant disease.

The test uses an antibody designed to find and attach itself to the wall of prostate cancer cells. Lymph nodes that have been invaded by prostate cancer cells appear as "hot spots" on the test. In order to optimize information obtained from ProstaScint imaging, it is now recommended that all studies be performed with either CT or MRI fusion.

Note:

ProstaScint is a highly complex test to execute and read. It also requires meticulous preparation by the patient. To receive the most accurate ProstaScint results, is highly recommended that you network within your support groups to find the 'artists' in this field.

ProstaScint Fusion Imaging

ProstaScint fusion imaging is used to aid in scan interpretation. Fusion imaging combines ProstaScint imaging with CT or MRI imaging to provide a uniquely detailed fusion image of high diagnostic quality.

How it works: Patients receive an intravenous injection of ProstaScint during their first visit. (No adverse reactions or side effects are anticipated from the injection.) A whole body scan is followed by a dual isotope single photon emission computed tomography (SPECT) scan of the pelvis and abdomen which takes about 45 minutes to complete.

As with any diagnostic tool, it should not be relied upon alone in a vacuum, but can contribute additional important information that patients and their physicians may require to make well-informed decisions regarding their treatment.

Sources:
1. Update on ProstaScint®: CT and MRI Fusion as Diagnostic Tools
   By Samuel Kipper, M.D., Pacific Coast Imaging, Irvine, CA
2. medicalimagingmag.com
3. diagnosticimaging.com/
4. prostateline.com/

ProstaScint® is a product of the CYTOGEN Corporation, Princeton, NJ
Toll Free: (800) 833-3533
Phone: (609) 750-8200
Fax: (609) 452-2476

A list of ProstaScint sites, including those with fusion, is located at the Cytogen website www.cytogen.com/professional/prostascint/pie.php
Understanding PSA

Anyone dealing with prostate cancer is aware of the PSA (Prostate Specific Antigen) test, which detects levels of a protein produced by cells of the prostate gland. While the efficacy of PSA test alone as a diagnostic tool continues to be closely scrutinized, it is still considered one of the most critical elements in determining your response to treatment or the status of the disease.

It is important to be aware of the subtle nuances of PSA testing. Since each person’s prostate gland produces a different level of PSA, the dynamics of PSA, such as PSA recurrence (PSAR), PSA velocity (PSAV) and PSA doubling time (PSADT) are important reflections of cell growth. (See sidebar for definitions of terms.)

For example: a high PSA velocity and a short PSA doubling time is consistent with systemic disease at initial diagnosis and in PSA recurrence after any form of treatment.

What impacts PSA testing? The following activities or events can impact the outcome of a PSA test. It is important for you and your doctor to work closely together to appropriately schedule a PSA test to generate the most accurate and meaningful results.

1. Prostate manipulation by DRE
2. Vigorous exercise that may involve pressure on the prostate such as bicycling, motorcycling, or horse back riding.
3. Sexual activity involving ejaculation within 48 hours of PSA testing
4. PSA testing with five weeks of transrectal ultra-sound of the prostate or Foley catheter insertion into the urethra, or other instrumentation of the prostate or nearby tissue.

Sources:
1. Us TOO website: http://www.ustoo.org/PDFs/CDC_PCa_Screening_Guide.pdf
2. Phoenix 5 website: www.phoenix5.org/glossary/glossary2A.html

PSA Recurrence (PSAR): a rise in PSA after a treatment intended to eradicate or control prostate cancer.

PSA Velocity (PSAV): the rate of increase in PSA expressed in nanograms per milliliter per year.

PSA Doubling Time (PSADT): The time it takes for the PSA value to double. This is used to help predict the possibility of metastasis and make treatment decisions.
PSA – Recurrence or “Bump”

Some patients experience a temporary rise in PSA after completion of brachytherapy (also called internal radiation therapy, seeding, interstitial radiation therapy (IRT), implant radiation) after first having a decline in PSA. The average time to PSA ‘bump’ or ‘bounce’ is 18-20 months. This phenomenon is believed to be the result of radiation induced prostatitis and not due to prostate cancer recurrence. It is important to be aware of this phenomenon to avoid a misdiagnosis of PSA recurrence and unnecessary treatment.

Sources:
2. www.cancer.prostate-help.org/cahdrbum.htm
3. www.phoenix5.org/books/Primer/Figure43PSAbump.html
4. www.psa-rising.com/med/ebr/psabounce1004.htm - 10k
5. www.oncolink.com/library/article.cfm?c=2&s=43&id=539

Additional important tests

Testosterone –
The hormone that promotes the development and maintenance of male secondary sexual characteristics. It is believed to comprise about 90 percent of the androgens in a man's body. Most of the testosterone is produced in the testicles. Some is also produced at the adrenal glands. Halting the production and conversion of testosterone is the primary objective of hormone therapy.

Dihydrotestosterone –
The male hormone that is active in the prostate gland. It is made when the enzyme 5-alpha reductase converts testosterone to dihydrotestosterone, which stimulates the growth of the prostate gland.

Note: Both these measurements provide valuable information to you and your doctor about the nature of your disease, such as activity level or the rate of progression. While the actual number produced by the test is noted (like PSA testing), more importantly, the movement of that number over time is vital to assessing the body’s response to disease and treatment.
**Patient Profile**

**Russ**  
Diagnosed: 1998 at age 58  
PSA @ 27, Gleason @ 6 or 7, Stage T1c-T2b

**Initial response:**

“After years as an engineer, I approached this problem like I would any engineering problem. I got on the phone and talked to as many people as I could right away. I also attended my first Us TOO support group meeting within one week of diagnosis (and still regularly attend today). I attended a major conference on prostate cancer within two months of diagnosis. I also used the internet, scoured books stores and went to the library.”

**Initial Treatment:**

3D Conformal external beam radiation and Androgen Deprivation at the same time and then continued for 2 years.

**Follow Up Treatment:**

Remained on hormone therapy for two years after treatment. Has since done intermittent hormone therapy (allowing the PSA to rise then retreating) in response to testing results (PSA velocity, testosterone and DHT). Lupron, Casodex, Proscar, Avodart, Actonel and supplements.

**Suggestions:**

1. Educate yourself and find support.
2. Be actively involved in your health and your care. Be careful selecting treatment and find a doctor who is a pro in the area you are considering.
3. Keep a log of your treatments, medications, responses and results (Note appointment dates, changes in meds, tests, timing, and results.) Get copies of your records from your doctor and keep them in a folder with all your records.
4. Track your PSA test results (consider ultra-sensitive PSA testing as well as standard PSA testing.) Track the velocity, the rate of climb, and the doubling time. These are critical indicators in assessing your health.
5. Track your testosterone and DHT (Dihydrotestosterone) levels as well

**Additional ways I care for myself:**

1. Active participation in support groups
2. Daily roller blading (100 miles per month)
3. Weight-lifting three times per week for bone health/integrity
4. Strict diet (No red meat or dairy. Sugar & calorie restriction. Seven fruits & vegetables each day.)

**Present Status**

Feel confident that prostate cancer is under control (on fourth 16 month cycle of IADT) with PSA dropping to <0.04. Physically and mentally active with minimum bother from side effects. Roller blade 100 miles per month, run a research and engineering business and participate in numerous Us TOO and government prostate cancer research and support efforts.
Treatment suggestions for localized disease

It can be frightening and frustrating if you have experienced a relapse or the cancer is not responding to current treatment. Fortunately, a variety of existing therapies are available, and new therapies are being developed.

This section discusses the current treatment options for cancer that has returned after treatment or for cancer that is no longer responding to hormone therapy, specifically recurrent cancer that is still localized.

Salvage Surgery:

Salvage surgery has been most successful when there is a recurrence of prostate cancer after a primary radiotherapy.

Advantages:
The surgery has been found to be successful when the patient is young and generally healthy, with truly organ-confined disease that was determined prior to radiotherapy and is also confirmed to be still present prior to the salvage radical prostatectomy.

Disadvantages:
Most common incidents of complications are urinary extravasation and bladder neck contracture.

Sources:
5. www.prostatecancerfoundation.org
7. www.oncolink.com/ - Reuters Health Posting Date: May 5, 2005
Radiation Therapy

There are numerous radiation techniques. Each technique uses high-energy rays or particles to kill prostate cancer cells or prevent cancer cells from growing and spreading. Radiation is generally used to treat prostate cancer that has not spread beyond the prostate (Stages T1 and T2). It is often used in combination with hormone therapy if cancer cells have spread beyond the prostate to nearby tissues (Stage T3). It may be used for pain relief in prostate cancer that is no longer responding to hormone therapy and has spread to other tissues in the body, primarily the bones (Stage M+).

Radiation therapy techniques:

- **External Beam Radiation Therapy (EBRT)**: radiation administered outside the body, usually in brief daily sessions for several weeks.
- **Intensity modulated radiation therapy (IMRT)**, minimizes radiation damage to normal tissues. The newest advance in radiation therapy.
- **Proton Beam Therapy (PBT)**: uses proton beams instead of x-rays to kill cancer. It is the most precise form of radiation, traveling through non-cancerous areas to rest directly on the targeted area. The precision of this method allows for stronger doses of beam radiation with minimal damage to surrounding tissue.
- **3-D Conformal Radiation Therapy (3DCRT)**: this improvement in radiation treatment allows closer targeting of the prostate gland. The most cutting edge technique combines 3DCRT and IMRT, which more selectively focuses the dose of radiation on prostate cancer cells.
- **Internal Beam Therapy (brachytherapy)**: radiation comes from small radioactive seeds (about the size of a grain of rice) inserted directly into the prostate that administer a constant dose of radiation for a few weeks to a year. Seeds are inserted while under anesthesia, and are too small to cause discomfort.
- **High-Dose Rate (HDR) Brachytherapy**: short-term internal beam therapy that uses higher dosage, non-permanent seeds. Because the seeds are implanted for a much shorter amount of time (approximately 1 hour), there is less likelihood of them migrating in the body.

Source: http://www.ustoo.org/Treatment_Options.asp#Radiation%20Therapy

Resources

1. EBRT: Us TOO
   International Prostate Pointers online bulletin board - www.prostatepointers.org/mailman/listinfo/ebrt

2. The National Association of Proton Therapy website: www.proton-therapy.org/.

Radiation therapies (continued)

Advantages of Radiation Therapy

- May allow patient to avoid major surgery
- May cure prostate cancer in its early stages and may help extend life or eliminate symptoms in later stages
- Side effects can be minor and disappear after therapy stops, especially when the latest IMRT and seeds techniques and equipment are used
- This treatment can be very effective when performed by a radiation expert.

Disadvantages of Radiation Therapy

- May cause damage to healthy cells, leading to side effects like:
  - Tiredness
  - Skin reactions
  - Frequent and painful urination
  - Upset stomach
  - Diarrhea
  - Rectal irritation or bleeding
- The vascular tissues surrounding the prostate are damaged by the radiation. This damage will progress and continue for many years, possibly causing impotence
- All radiation therapy is associated with decreased red blood cells, white blood cell, and platelet counts
- The amount of radiation a human body can accept is limited, making future use of radiation therapy in most situations dangerous.
Salvage – Cryosurgery: Also called ‘cryo’.

Salvage Cryo-surgery uses sub-zero temperatures to freeze and immediately kill sections of the prostate cancer tissue. This technique is used to treat localized prostate cancer in stages T1 and T2.

This procedure is performed under anesthesia and uses ultrasound-guided placement of cooling probes into the prostate. Cryo surgery can be combined with hormone therapy to reduce the size of the tumor prior to freezing.

Advantages of Salvage Cryosurgery
- Avoids major surgery
- Less likely to cause urinary tract damage, obstructions, or bowel difficulties than radiation
- Procedure takes an hour and a half or less and patients often fully recover within days
- Protects healthy tissue from damage

Disadvantages of Cryosurgery
- Impotence due to nerve damage is a common occurrence
- Urinary incontinence can occur but is rare
- Approximately 2% of men develop an abnormal tissue mass (fistula) that connects the rectum and the bladder that may require surgery to repair

You can read or join discussions about cryosurgery at the Us TOO International Prostate Pointers online bulletin board called “Ice Balls”

www.prostatepointers.org/mailman/listinfo/iceballs

The National Cancer Institute has a fact sheet on cryosurgery:

http://cis.nci.nih.gov/fact/7_34.htm
Treatment suggestions for non-localized disease

When cancer has spread beyond the prostate, complete removal of the prostate or destruction of cancer tissue by radiation or cryosurgery is uncommon. For state T3 and T4 prostate cancer, androgen deprivation therapy (ADT, also called hormone therapy) is used to slow the rate of cancer cell growth and spreading to other areas of the body.

Hormone Therapy: Prostate cancer cells utilize male hormones (such as testosterone) to grow. Hormone therapy, or androgen deprivation therapy, decreases current production of testosterone by the testicles so that cancer cell growth slows down. Drug treatment that reduces testosterone levels, reduces the effect of testosterone or adrenal androgens from acting on the prostate, and reduces conversion of testosterone to dihydrotestosterone (DHT). Dihydrotestosterone is a powerful stimulus for prostate cell growth.

Side effects of hormone therapy: Common side effects of reducing male hormone activity by hormone therapy (listed in order of most to least common):

- Bone loss leading to osteopenia (bone loss) or osteoporosis (weakening of the bone integrity)
- Loss of muscle mass (sarcopenia) and increase of body fat
- Hot flashes
- Anemia (decreased level of red blood cells)
- Depression
- Gynecomastia (breast enlargement)
- Reduced libido
- Impotence

Source: www.ustoo.org
Resources: www.cancernews.com/hrt.htm
www.prostate-cancer.org/resource/gloss_a.html
Types of Androgen Deprivation Therapies

Luteinizing hormone-releasing hormone (LHRH Therapy): The administration of an injectable luteinizing hormone-releasing hormone (LHRH) agonist or antagonist that causes a drop in testosterone levels in the body.

LHRH options currently available:
- Lupron® (leuprolide acetate)
- Eligard® (leuprolide acetate)
- Viadur® (leuprolide acetate implant)
- Zoladex® (goserelin acetate)
- Trelstar™ (triptorelin)
- Plenaxis™ (abarelix)

Advantages of LHRH Agonists
- Easy administration of injections monthly or every 3, 4, or 12 months
- Treatment with LHRH agonists is as effective as orchiectomy in reducing testosterone levels
- Side effects can be reversible upon termination of the treatment so as to allow intermittent androgen deprivation (IAD) therapy
- Causes immediate suppression of testosterone levels without the initial “flare” except for tumors that are large and next to the spine
- No need for antiandrogen therapy unless the tumor is large and next to spine

Disadvantages of LHRH Agonists
- Side effects of hormone therapy may be difficult to treat and hard for some people to accept
- In a few patients, LHRH agonist therapy may cause a brief initial rise in symptoms “testosterone flare” before the testosterone level begins to fall
- Requires monthly injections or every 1, 3, 4, or 12 months
- Less clinical data available for LHRH antagonists compared with LHRH agonists. (*See sidebar)

Sources: www.ustoo.org
www.prostatecancer.about.com/od/glossar1/g/LHRH_analog.htm
www.prostate-cancer.org/resource/ gloss_l.html

Resources:
- www.lupron.com
- www.eligard.com
- www.viadur.com
- www.zoladex.com
- www.trelstar.com
- www.plenaxis.com

*ANTAGONISTS vs. ANALOGS

LHRH antagonists work by directly inhibiting LHRH so that there is no more production of testosterone. In contrast, the LHRH analogs stimulate the LHRH receptor and cause initial production of testosterone for one to two weeks which is then exhausted.
Androgen Deprivation Therapies (continued)

Orchiectomy:
An operation that removes the testicles, which produce 95% of the body's testosterone.

Advantages of Orchiectomy
- One-time procedure
- Effective, permanent reduction in testosterone
- Patients typically go home the same day as the surgery
- Cost (relatively inexpensive) and convenience

Disadvantages of Orchiectomy
- Side effects, such as reduced or absent sexual desire, impotence, and hot flashes and emotional impact make this procedure difficult for some patients to accept
- Irreversible surgical procedure
- In some cases, may require hospitalization
- Will not allow for intermittent androgen deprivation (IAD) therapy

Antiandrogen Therapy
The administration of a drug called an antiandrogen that blocks the action of male hormones, including testosterone and androgens released by the adrenal glands. Used in combination with LHRH agonist therapy (Lupron) in a strategy called maximal androgen blockade (MAB) or combined androgen blockade (CAB).

Source: www.ustoo.org
You can read or join discussions about CAB at the Us TOO International Prostate Pointers online bulletin board called “CAB”
http://www.prostatepointers.org/mailman/listinfo/chb
Antiandrogen Therapy (continued)

Antiandrogens currently on the market:

- Casodex® (bicalutamide)
- Eulexin® (flutamide)
- Nilandron® (nilutamide)
- Androcur® (cyproterone)

Advantages of Antiandrogen Therapy: May provide a small survival advantage over either orchiectomy or LHRH analog therapy alone.

Disadvantages of Antiandrogen Therapy: In addition to common side effects of hormone therapy, you also may develop the following symptoms:

- Breast pain or enlargement
- Diarrhea
- Gastrointestinal pain
- Anemia
- Adverse effects on liver function (possible elevation of liver enzymes that must be monitored)

Resources
- www.cancerhealthonline.com
- www.MedicineNet.com
- www.casodex.net/
- www.ProstateLine.com

5-alpha Reductase (5-AR) Inhibitors: Block conversion of testosterone to DHT, a more potent stimulator of prostate cell growth than testosterone.

The 5-AR inhibitors currently on the market are:

- Proscar®, Propecia® (finasteride) – reduces DHT levels in the blood by 70% and 80%-90% on prostate
- Avodart® (dutasteride) – reduces DHT levels in the blood by 98% and can slow prostate cell growth

Source: www.ustoo.org & www.cancerhealthonline.com
**Estrogen Therapy**

**Estrogen Therapy:** Administration of estrogen hormones lowers testosterone production and has some direct *apoptotic** effects on both androgen-dependent and androgen-independent prostate cancer cells. The following are some estrogen therapies that are currently available:

- DES (diethylstilbestrol)
- Stilphosterol® (stilbestrol diphosphate)
- Honvan® (fosfestrol tetrasodium)
- Estradurin® (polyestradiolphosphate)
- Estraderm® patch (estradiol) – only one small-scale trial has investigated the benefits of delivering estrogen through the skin (transdermal) to block testosterone production in men with prostate cancer. In that study, the patch was successful in reducing testosterone levels, with fewer cardiovascular or other side effects. Phase III Trials involving large number of patients are currently comparing the effects of patch and injected forms of estrogen in men with prostate cancer.

**Advantages of Estrogen Therapy**

- Does not induce androgen-independent cancer growth
- Can dramatically slow the growth of some prostate cancer cell types
- Inexpensive

**Disadvantages of Estrogen Therapy**

- Will cause gynecomastia***unless prevented by breast irradiation.
- Depending on the rate of administration, it may promote hyper coagulation of blood, causing blood clots in the legs, lungs, and brain. Blood thinners may need to be taken to prevent these complications.
- Causes decreased libido and impotence.

Source: www.ustoo.org & www.cancerMBA.com

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**Apoptotic:**
(Apoptosis): referring to genetically "programmed" cell death, a natural process in which DNA-damaged or otherwise unwanted cells are eliminated.

Source: Research Initiative Treatment Action (RITA!); Vol 8, No. 2 Spring 2003

**Gynomastia:**
The term comes from the Greek words gyne meaning "woman" and mastos meaning "breast." In practical terms, this means abnormally large breasts on men.

Source: www.gynecomastia.org

RESOURCES
www.CancerMBA.com
Male Health Centers: www.malehealth.com/HTM/L/BSj_print.html
eMedicine: www.emedicine.com/med/topic934.htm

Source: www.ustoo.org & www.cancerMBA.com
**P450 Enzyme Inhibitors**

The P450 enzymes are involved in the synthesis of several hormones, including testosterone, that stimulate prostate cancer cell growth. Inhibitors of these enzymes can decrease the levels of testosterone and adrenal androgens, and have direct cytotoxic (*see sidebar) effects on prostate cancer cells. Currently, the available enzyme inhibitor is a drug called Nizoral. *(Nizoral is ketoconazole** (see below) *used in combination with hydrocortisone.)*

**Advantages of P450 Enzyme Inhibitors**

- May still be useful in men for whom CAB has failed (who are androgen resistant)
- Reduces both testicular testosterone and adrenal androgen production
- Additional cytotoxic (*see sidebar) effect on prostate cancer cells

**Disadvantages of P450 Enzyme Inhibitors**

- Requires continued use of LHRH agonists or estrogen therapy to block pituitary stimulation of testicular hormone production (unless the patient had an orchiectomy)
- Non-selective effects on other cells may cause discomfort (nausea, gastric irritation)
- May have significant adverse effects on liver function (must measure liver enzymes)

**KETOCONAZOLE**

Definition: *(kee-toe-KON-uh-zole)* A drug that treats infection caused by a fungus. It is also used as a treatment for prostate cancer because it can block the production of male sex hormones such as testosterone in both the testicles and adrenal glands. Nizoral is a US brand name.

Source: [www.phoenix5.org/glossary/ketoconazole.html](http://www.phoenix5.org/glossary/ketoconazole.html)

*Cytotoxic:* any drug that has a toxic effect on cells; commonly used in chemotherapy to inhibit the proliferation of cancerous cells


Resource: www.nizoral.com

www.ustoo.com/Treatment_Options.asp
Hormone-resistant prostate cancer

HORMONE-RESISTANT PROSTATE CANCER: (Also called hormone refractory cancer.) Prostate cancer that is no longer responsive to hormone therapy is referred to as hormone-resistant prostate cancer or androgen-independent prostate cancer. There is currently no cure for hormone resistant prostate cancer. However, several therapies can extend life and reduce pain and discomfort. Treatment of hormone-resistant prostate cancer that has metastasized (Stage N+ and M+) may require systemic radiation therapy or chemotherapy.

Systemic Radiation Therapy: Can be used to reduce pain and symptoms associated with metastasized prostate cancer that does not respond to hormone therapy (Stage N+ and M+).

See the preceding section on radiation therapy (page 12-13) and the section on treating pain associated with advanced prostate cancer (page 25) for more details.

Estrogen Therapy: Administration of estrogen hormones lowers testosterone production and has some direct apoptotic effects on both androgen-dependent and androgen-independent prostate cancer cells.

See the preceding section on estrogen therapy (page 19) for more details.

P450 Enzyme Inhibitors:

See the preceding section on P450 Enzyme Inhibitors (page 20) for more details.

Sources: www.ustoo.org
http://www.prostateinfo.com/patient/treatment/other.asp
www.prostatecancerfoundation.org
Hormone Resistant Prostate Cancer (continued)

CHEMOTHERAPY: Cancerous tumors are characterized by cell division, which is no longer controlled as it is in normal tissue. "Normal" cells stop dividing when they come into contact with like cells, a mechanism known as contact inhibition. Cancerous cells lose this ability.

Chemotherapy, the administration of drugs (orally or via injection), can be effective at killing cells that are rapidly growing and dividing in an uncontrolled manner. Chemotherapy can be an important element of the ‘team approach’ to prostate cancer treatment.

Therapies are more targeted than ever and more accurate in their attack of cancer cells without damaging the normal cells, thus leading to fewer side effects. Development of chemo-protective agents, drugs that are used with certain types of chemotherapy, also protect the body from or minimize the side effects.

The following is a list of the currently available chemotherapy drugs:

- Novantrone® (mitoxantrone; specifically approved for hormone resistant prostate cancer)
- Taxotere® (docetaxel)
- Taxol® (paclitaxel)
- Emcyt® (estramustine)
- Adriamycin® (doxorubicin)
- Cytoxan® or Neosar® (cyclophosphamide)
- Paraplatin® (carboplatin)
- Thalomid® (thalidomide)

Note: Recent Phase III randomized studies have shown that Taxotere® in combination with either Prednisone® or Estramustine® can modestly increase survival in patients with hormone resistant prostate cancer.

Sources: www.ustoo.org
www.urologyhealth.org
www.chemocare.com
“I could not focus and felt panic until my wife woke me up to the fact that we could deal with this if we stopped being passive and took charge.”

(On low-dose Taxotere)... “I had no hair loss, minimal impact in eating (lost taste for red wine), and virtually no loss of energy level.”

“Discuss your diet with your doctor or a knowledgeable nutritionist to make sure you are getting all the nutrition you need. View these changes as an opportunity to try something new.”

“Share your journey with others, especially your spouse, partner or significant other. My wife virtually saved my life.”

The medical information and procedures contained in this booklet 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.
Emerging Treatments

Every day, researchers work to find new ways of treating prostate cancer. Only a small percentage of these new treatment possibilities will ever be approved by the United States Food and Drug Administration (FDA) and subsequently make it to market. Some fail in clinical trials or will be found to have side effects that are too toxic.

Until new medications that can cure prostate cancer are found, research is being conducted to discover medications that can:

- increase survival times
- delay the progression (spread) of the cancer
- help to maintain or improve the quality of life of patients,
- and have tolerable or no side effects.

Promising research is currently underway in the area of new, so-called “targeted” medications. Targeted medications work by attacking or blocking targets (small proteins or molecules in the body) that are specifically involved in the growth and spread of tumor or cancer cells. Medications of this type have already been developed to treat other common cancers, such as colon and breast cancer.

Ideally, these targeted medications would be administered as convenient, oral capsules or tablets taken once a day, rather than delivered by injection in a doctor’s office or in a hospital setting.

Note:
Participating in ongoing support groups or online discussion communities can be quite helpful when seeking new information and resources about emerging treatments.

Educate yourself.
Work closely with your doctor.
Network with other prostate cancer patients.
You are your best advocate.

Source: www.ustoo.org

Emerging Treatments
Atrasentan (Xinlay™/Abbott)
Bortezomib (Velcade®/Millennium)
Calcitriol (Novacea)
Erlotinib (Tarceva™/Genentech)
GVAX® (Cell Genesys)
Gefitinib (Iressa®/AstraZeneca)
Imatinib (Gleevec®/Novartis)
Ixabepilone (Bristol-Myers Squibb)
KOS-862 (Roche)
PROSTVAC®-VF (Therion Biologics)
Provenge® (Dendreon)
Satraplatin (GPC Biotech)
Vitaxin™ (Medimmune)
ZD 4054 (AstraZeneca)
Men are taught at a very early age to disregard or minimize their pain. The words, “big boys don’t cry” is found deep in the ideology of most men.

While prostate cancer may not produce painful symptoms when in its early stages, pain is often associated with prostate cancer that has metastasized to the bones.

While pain is unpleasant, and can be excruciating, it is a vital indicator of a problem which requires prompt medical attention. Pay close attention to pain. If it lasts more than 7-10 days, it is vitally important see your doctor. Do not wait. Do not try to ‘gut out the pain’. There are options for treating and reducing your pain. The first step is to acknowledge the pain and seek help.

External beam radiation therapy (ERBT) may ease pain caused by bone metastases and it may also delay the progress of the disease. Pain associated with a blocked urinary track may be reduced by surgery to open the urinary track. Beneficial drugs include steroids and other ‘second-line’ hormonal therapies, as well as pain killers. While pain cannot be entirely eliminated, it can be effectively relieved in the majority of patients.

Pain is a vitally important indicator that something is wrong.
Pay attention to your pain and seek medical attention.

Note:
Network with others through a prostate cancer support group or online discussion community for suggestions about medical and non-medical approaches to pain management.

Source:
www.ustoo.org
Clinical Trials

Many of the new therapies for prostate cancer are being tested in clinical trials. Clinical trials are organized studies conducted with patients, and are required by the FDA before a particular treatment can be made available to the public. Clinical trials answer specific questions about new treatments. They also test new ways of using established treatments, as well as testing the safety and effectiveness of a treatment.

Every clinical trial is designed to answer a specific set of questions about a treatment. Each study enrolls patients with certain types and stages of cancer and certain health status. If you fit the criteria for a clinical trial, you may be eligible to take part.

You may be referred to a trial by your doctor or by a doctor who knows your case. You must have a reasonable understanding of the possible risks and benefits of a clinical trial and be freely willing to take part in it. All patients in clinical trials are carefully monitored during and after participating in the trial. Be sure to talk to your doctor about whether you would be eligible to participate in a clinical trial.

Types of Trials: Clinical trials are carried out in phases, each designed to find out a certain type of information about a particular treatment. Information from each phase is built upon in the next phase; all of the information collected on the treatment is used to obtain approval from the FDA for its use.

Phase I Trial: Involves a small number of patients and tests how to give a treatment and how much can be given. A phase I trial identifies any side effects caused by the treatment.

Phase II Trial: Involves 20-50 patients with a particular stage or type of cancer. A phase II trial tests the effectiveness of the treatment in treating cancer and determines the frequency of side effects caused by the treatment.

Phase III Trial: Involves large numbers of patients (in the thousands). It compares the effectiveness and side effects of a standard treatment and the new treatment in treating cancer. Patients in these trials are assigned randomly to receive one of the treatments being studied.

For comprehensive information regarding current clinical trials, visit: www.clinicaltrials.gov

Additional Clinical Trial Resources
- www.bethesdatrials.cancer.gov
- www.centerwatch.com/patient/studies/cat36.html
- www.oncolink.upenn.edu/
- www.nci.nih.gov/clinicaltrials/prostate-cancer-updates
- www.cancer.gov
- www.emergingmed.com
Advanced Disease

Understanding Treatment Choices for Prostate Cancer
by Us TOO International and the National Cancer Institute
Article reprinted with permission.

Approximately three-quarters of all newly diagnosed prostate cancers are clinically localized (Stage I or Stage II). About 15% are Stage III and 11% are Stage IV.

If your cancer is Stage III it is a regionalized tumor that has spread beyond the prostate – through the capsule that encloses the prostate and perhaps into the seminal vesicles. However, it has not reached the lymph nodes or any more distant sites in the body.

The long term prospects for men with Stage III prostate cancer depend on the extent of the disease. Once the cancer has broken through the prostate capsule, chances that the disease will progress in the next 10 years are 50-50.

If your prostate cancer has spread to the nearby lymph nodes or to distant parts of the body, it is called metastatic prostate cancer. Hormonal therapy will generally improve the symptoms and delay the progress of the disease for another 2 to 3 years. If just the lymph nodes are involved, a man may use hormonal therapy to delay the progress of the prostate cancer even longer.

However, the vast majority of those with positive lymph nodes at the time of getting hormonal therapy will remain at risk of developing additional metastatic disease within 10 years of treatment. Bone metastases tend to be less responsive to hormonal therapy.

Source: www.ustoo.org

“Your empowerment as a patient enables you to help steer the course of your illness and ensure a safe passage.”

Source:
Over time, metastatic prostate cancer often stops responding to hormonal therapy. Advancing disease may be accompanied by painful symptoms, usually involving the urinary tract or bones, along with weakness, fatigue and weight loss.

Radiation may ease pain caused by bone metastases and it may also delay the progress of the disease. Surgery can be helpful in opening a blocked urinary track. Beneficial drugs include steroids and other “second-line” hormonal therapies, as well as pain killers. While pain cannot be entirely eliminated, it can be effectively relieved in the majority of patients.

An important consideration to factor into your treatment decisions is that success is not guaranteed. As many as half of the apparently localized cancers turn out, at surgery, to have already spread. And up to one-fourth, despite apparently successful surgery, will produce a recurrence over the next several years.

In coming to a decision, you may find it helpful to thoroughly discuss your treatment options, including benefits and side effects, with your wife/partner. You may also consider contacting a local prostate cancer support group after consulting with your physician. Getting a second opinion and different perspectives can be very helpful.

You may want to take part in a clinical trial evaluating new approaches. For comprehensive information regarding current clinical trials, see page 26 of this booklet and visit www.clinicaltrials.gov.

Reference: Understanding Treatment Choices for Prostate Cancer by Us TOO International and the National Cancer Institute
Article reprinted with permission.
Living healthy

While it is vitally important to work closely with your doctor, those who are most successful are also actively involved in their own care every day. There are numerous ways to care for yourself and improve or stabilize your health. Some of the most valuable tools are readily available and either cost-effective or free.

The ways in which you can actively impact your health are:

- **Diet**
- **Exercise**
- **Lifestyle**
- **Attitude**
- **Emotional support**
- **Spiritual well-being**

Your doctor is your partner, but you are your best advocate. Maintain close contact with family and friends through this phase of treatment. Those who have a positive attitude and are actively involved in their lives live well... and longer.

Many of the suggestions in this section are consistent with recommendations from numerous health related resource groups. If you have been taking good care of your health, keep it up! Add a few of these ideas to your daily regimen. If you have not yet adopted some of these basic health tips, now is the time to get in step with the program toward vibrant overall health. Most suggestions easy to adopt, require little or no formal training, and no specialized equipment. They do require, however, an active commitment to new habits and ideas.

Although the causes of prostate cancer aren’t fully understood, eating well, getting plenty of rest, and exercising regularly may improve your health and provide improved quality of life too.
Dietary Suggestions

‘Eating well’ means more than simply eating enough to feel full. Eating well means adding vital nutrients to your diet and, perhaps, eliminating certain foods that are may be harmful to your health from your diet. Our traditional Western diet, marked by a high intake of saturated fat from meat and dairy and a low intake of fiber from fruits and vegetables, is associated with an increased risk of prostate cancer and more malignant tumors.

It is widely accepted that testosterone stimulates prostate cell growth, and what you eat can change your testosterone levels. Limiting your intake of high-fat foods, which can stimulate testosterone, and incorporating foods naturally low in saturated fats, such as fruits and vegetables, grains and fish, may improve your overall health.

There are many foods and supplements that can improve your immune function as well. Supplements, however, can provide far more of a component or compound than is recommended by the National Academy of Sciences. It is recommended to add foods, when possible, to your diet that contain antioxidants, which can prevent cell damage and may enhance immune function.

For example:

**Lycopene**s may inhibit the growth of prostate cancer cells. Foods include grapefruit, tomatoes, and tomato products.

**Selenium** may directly impact prostate cancer cells promoting cell death. Foods include garlic, whole grains, and seafood.

**Vitamin A and Carotenoids** may help your body regulate immune function and prevent or fight off infection. Foods include apricots, broccoli, carrots, peaches, squash, sweet potatoes and tomatoes. Blueberries are especially beneficial.

**Vitamin C & E** appear to counteract some of the negative effects of male hormones on prostate cells. Vitamin C foods include broccoli, citrus fruits, and leafy green vegetables. Vitamin E foods include whole grains, nuts and seeds.

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

Blueberries: Journal of Neuroscience 1999;19:8114-8121

Additional dietary suggestions specifically for those on androgen deprivation therapy, or hormone therapy.

Cut calories
Several medical papers indicate cancer needs calories to grow. Eat to meet your body’s specific needs, and make wise, informed choices about your calorie intake.

Reduce fat in your diet
High fat diets are linked to increased tumor growth.

Get away from red meat
The gene that produces the enzyme that helps digest red meat is highly active in prostate cancer cells. Red meat is also a source of saturated fats.

Include deep water fish
Increase consumption of omega-3 fatty acids by eating deep-water fish (yellow-fin tuna, sardines, cod or haddock). These foods provide EPA/DHA, the fatty acid found in fish protects, that may protect against prostate cancer. EPA/DHA also available in supplements.

Whey protein
Researchers say whey protein contains the amino acid cysteine which is critical for the body’s production of glutathione which may aid in prostate cancer prevention. Good sources of cysteine are poultry, wheat, broccoli and eggs.

EPA/DHA
These supplements may inhibit prostate cancer growth and are available in most health foods stores.

Sources:
The Journal of the National Cancer Institute.
Bone Health

Men who are taking hormone therapy (ADT) for prostate cancer must be aware of the direct link between hormone therapy and bone loss/bone resorption. Bone integrity is linked to overall health so preventing bone resorption and excessive bone loss has become a critical part of prostate cancer management. Bone integrity issues are generally managed in prostate cancer patients with a treatment called bisphosphonates.

Poor bone health can be painful and can lead to fractures, hospitalization, and reduced mobility. Fractures also reduce the ability to exercise, which can negatively impact bone density, reducing overall muscle tone & fitness. Fractures can also be a significant contributor to mortality, especially in seniors, and poor spine health can lead to spine compression and paralysis.

Healthy bones tips and tools:

1. Measure your height in a doorway at home before beginning treatment.
2. Demand a bone density test PRIOR to treatment. If you are already in the treatment process, look back on older medical records and get the height measurement for comparison.
3. Get 15 minutes of sunshine per day to help fill your daily requirement of Vitamin D.
4. Pay attention to pain. If it lasts more than 7-10 days, see your doctor. Do not wait. Do not try to ‘gut out the pain’.
5. Pay attention to your diet. Make sure you get your daily dietary intake of calcium and Vitamin D which promote bone health.
6. Incorporate weight-bearing exercise (both aerobic AND resistance) into your daily activity; for example, moderate weight lifting and walking.

Sources:

Resource:

Note:
- Don’t let symptoms scare you. See them as a signal to get more information and take action.
- Maintaining your bone health will help maintain your quality of life.
Attitude is everything…

“This disease does not define me...”
Jim Keifert, 15 year survivor, Us TOO Board Chairman

It is commonly believed that a person’s attitude impacts their experience of life. Someone who is pessimistic and sees life as gloomy will have a very different experience each day that someone who is optimistic and see life as a grand adventure.

This is not simply ‘Pollyananna’ thinking. The body has very real responses to our thoughts. Based on our viewpoint, the body creates or reduces chemicals associated with stress, improving or harming immune function and countless other bodily functions accordingly. Although small amounts of stress can enhance immune function, chronic stress has the opposite effect.

Here are ten tips for reducing mental stress and creating better health:

1. Avoid violent movies, books, television programs. Go on a "news fast" by not reading the paper, listening to the radio or watching the news on TV for a week. Then try extending this for a longer period of time. Instead, read uplifting books and watch positive programs.
2. Associate with calm people.
3. Practice forgiveness and understanding, starting with yourself.
5. Appreciate nature. Slow down and smell the roses!
6. Tell yourself you love and appreciate yourself. Learn to mean it. If you can’t, get help understanding why.
7. Tell others you love them.
9. Practice saying positive affirmations daily.
10. Make a list every day of ten things you are truly grateful for. Journal.

Sources:
2. Smart Medicine for a Healthy Prostate - Natural and Conventional Therapies, Mark W. McClure, M.D., (NY: Avery Publishing Group, 2001)
Finding support...

Peer support, either in-person support groups or online support communities, can help cancer patients offer each other helpful advice and tips on how to get through treatment, recovery, and ongoing issues. A support group provides a forum for patients and their families to share stories, ask questions, and share the emotions of this challenging experience.

Benefits of participating in a support group include:

- preventing isolation
- sharing experiences and exchanging information
- lending support, encouragement, and hope
- enhancing self-esteem
- providing a cost-effective method of aiding cancer treatment.

Beyond the immediate emotional benefits of support groups, studies have shown that patients who attend regularly tend to live longer than those cancer patients who do not.

Us TOO has over 320 peer-to-peer support chapters worldwide and fourteen online discussion groups. Support chapters hold regular meetings for men living with prostate cancer and their family members. The meetings provide unbiased information from experts in areas related to prostate cancer, such as surgery, radiation, medications, nutrition, and psychology. Us TOO chapter meetings are free and open to all men, family, friends, and health professionals interested in prostate cancer/disease.

Looking for an Us TOO chapter or an online support discussion group?

- Visit the Us TOO website at www.ustoo.org.
- You may also contact the Us TOO headquarters at 1-800-80-US TOO (800-808-7866). In the Chicago area (630) 795-1002, 9am - 4:30pm CT.
- Online discussion & support: www.ustoo.org/Prostate_Pointers.asp

About Us TOO

Receiving the news that prostate cancer has returned or is not responding to treatment is traumatizing. Life is once again out of control and fear takes hold. Often, feelings of helplessness, guilt, isolation and anger resurface or emerge. No one needs to face these challenges alone.

Us TOO provides the forum for sharing, caring and learning through its many programs and services designed for both men with cancer and their loved ones. www.ustoo.org
Support for spouses, family members and companions…

Prostate cancer is a disease of the patient, the partner or spouse, and the family. While the patient experiences cancer in their body, those closest to the patient have an experience of prostate cancer that is very real.

The challenges of the caregiver may not show up on a lab chart or test result, yet they are often equally painful and traumatic. Their experience can leave them feeling helpless, confused and alone. Their lives are also dramatically impacted by the diagnosis and treatment of prostate cancer. They, too, experience the treatments, the doctor visits, interrupted sleep, sadness, fear and grief.

Tips and tools for companions and families

1. Caregiver self-care is just as critical as care for the patient. You can provide better care when you care for yourself.
2. Reach out for help from family, friends, support groups, your church and your community. You need not walk this path alone.
3. Remember to exercise regularly, eat a balanced diet and get enough sleep. These activities not only improve your health but your mental and emotional well-being as well. Journal about your feelings.
4. Offer to go to doctor appointments with your loved one, ask questions and take notes. You and your loved one are a team. Talk openly with your loved one about his condition and concerns.
5. Educate yourself on the latest treatment options, medications, and life-style suggestions.

YOU MATTER TOO.

YOUR EXPERIENCE OF PROSTATE CANCER IS REAL.

YOU NEED CARE AND SUPPORT TOO.

Resource:
The Circles of Love Companions & Families Care Kit, from Us TOO, Supported by an educational grant from Abbott Oncology.

Kit Includes:
1. The Circles of Love Collection: Personal stories from companions and family members of those fighting prostate cancer
2. Intimacy with Impotence: The couples guide to better sex after prostate disease.
3. What You Need to Know about Prostate Cancer.
5. Circles of Love Music CD

Available at: www.ustoo.org or call Us TOO at 630-795-1002
Fitness for overall health...

The tendency for men undergoing hormone treatment is to become sedentary. A sedentary lifestyle can lead to depression, weight gain and an increase in cholesterol.

Regular exercise prevents obesity, which is a risk factor for many diseases, including cancer. Exercise has been shown to strengthen the bones and immune system, and improve digestion, circulation, and the removal of waste from the body.

When adding exercise into your life, do what you are able, even five minutes, then rest if necessary. Increase your level of exercise as you are able.

The following forms of exercise can be beneficial for improving your bone integrity, overall health, and energy level:

- Walking
- Weight resistance exercises
- Yoga
- Stretching
- Tai chi
- Meditation
- Trampoline (small rebounder)
- Nordic Trac
- Rowing
- Roller Blade

**Fitness Suggestions**

*Rather than…*

- …waiting for the elevator, take the stairs
- …taking a coffee break, take a 10 minute stretch break or a quick walk
- …lying on the couch to watch TV, use a treadmill or a stationary bike instead.

**Reducing stress and creating better health:**

*Tai chi – (ti – CHEE):* Tai Chi is a series of gentle physical movements, and breathing techniques, with mental and spiritual intent, which allows you to experience a meditative state. It is calming and rejuvenating, and assists the body and mind to maintain balance, and exercises the body, mind and spirit, together with the internal organs.

*Source:* healersoftheworld.com

Visit your local library for Tai Chi instructional videos, such as:

- *Tai Chi for Busy People*
- *Tai Chi for Seniors*

*Resource:*

Diet, Stress Reduction May Slow Prostate Tumors, Tuesday December 4, 2001, NEW YORK (Reuters Health)
Stan Diagnosed: 1991 at age 71
PSA @ 8.0, Gleason @ 5, Stage: Not available

Initial response:
“...I moved into action. I was disappointed with the diagnosis, but I knew I
needed to do something. While my doctor was my primary source of
information, I also checked books out of the library and bought books too.
Over the first year I accumulated a lot of information.”

Initial Treatment:
“I was diagnosed with prostate cancer after two biopsies in the summer of 1991
at age 71. In December of 1991 I had a radical prostatectomy. At the time the
surgeon said there was no sign of cancer in the glands around the prostate.”

Follow Up Treatment:
After about two years, my PSA started going up and eventually got to about
8.0/9.0. My doctor sent me to a specialist for external beam radiation. After
five weeks my PSA started to drop, eventually reading about 1.0.

After another two years my PSA began to go up, reaching about 9.0. At that
time, my oncologist suggested hormone therapy. At first I received therapy
as shots every three months, then at four month intervals. I now have had my
third insertion of the slow release hormone (like Lupron) in my left arm. I
have received hormone therapy for almost 8 years. Under hormone therapy,
my PSA has been fluctuating between 0.1 and 0.4, and is currently at 0.4.

Additional ways I care for myself:
1. My diet is high in fruits and vegetables and some meat. I eat fish twice a
   week.
2. I attend Us TOO/American Cancer Society “Man to Man” meetings and find
   them interesting and helpful.
3. I’m not reticent to talk to anyone about prostate cancer.
4. During all this time I have had the support of a wonderful wife and family
   and lots of understanding friends.
5. I take vitamins & minerals in geezerly-doses.

Patient’s Present Status
“I just had my 84th birthday this month. Until I had a hip replacement I was an
active runner and backpacker. Currently I am recovering from a broken femur,
but feel fine. I have never had any symptoms of prostate cancer. My life has
been good.”
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.
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THIS TABLE IS FOR YOUR TRACKING PURPOSES. YOU CAN RECORD YOUR PROGRESS HERE OR MAKE COPIES OF THIS PAGE TO USE OVER AND OVER.
About Us TOO

Us TOO International Prostate Cancer Education and Support Network

Us TOO is a grassroots organization started in 1990 by prostate cancer survivors to serve prostate cancer survivors, their spouses/partners and families. We are a 501(c)(3) not-for-profit charitable organization dedicated to communicating timely and reliable information enabling informed choices regarding detection and treatment of prostate cancer. Ultimately, Us TOO strives to enhance the quality of life for all those affected by prostate cancer.

No one needs to face prostate cancer alone. Us TOO provides the forum for sharing, caring and learning through its many programs and services designed for both men with cancer and their loved ones.

In addition to providing education and support programs, Us TOO is an active advocate for patients. We are committed to making sure patients have access to the programs, medications, treatments and health care professionals they need for the best possible outcomes.

Us TOO International Programs & Services:

- Special Patient Education Resources
- Web Based Communities
- Newsletters
- Advocacy
- Circles of Love Companions & Families Support & Care Kit
- Toll-Free Patient Support Line
- Minority & Underserved Populations Outreach
- Awareness
- Volunteer Opportunities
- Newly Diagnosed Patient Resource Kit
- Online Store

"To know the road ahead, ask those coming back.”
– Chinese proverb

Us TOO International Prostate Cancer Education and Support Network
5003 Fairview Ave  Downers Grove, IL 60515
Phone: 630-795-1002  URL: www.ustoo.org
Jim
Diagnosed: 1999 at age 60
PSA @ 5.8, Gleason @ 8, Stage T1c

Initial response:
“My dad and his brother both died from prostate cancer, so I had been watching the rise in my PSA with some concern. When my PSA went from 3.6 in May 1998 to 4.8 in August 1998, I had a DRE, an ultrasound and a biopsy. These tests all proved negative. However, because of my own family history, I began to research on the internet and I read several books. I felt that, as the patient, I needed to gain more information and insight. Therefore, I began to monitor my PSA more frequently than was recommended.”

Initial Treatment:
Feb. 1999     PSA – 5.7 – an antibiotic was given
June 1999     Underwent a second prostate biopsy and DRE – negative
Oct. 1999     My third biopsy was positive, with a Gleason 8, therefore I renewed my research; spoke to several practitioners, attended a 2 day Prostate Cancer Conference and reviewed my options, before choosing to have my prostate removed.
Dec. 1999     Radical prostatectomy – no lymph node involvement- Outlook good

Follow Up Treatment:
PSA remained at zero for 2 years
May 2002     PSA – 0.1
June 2003     PSA – 0.6
July 2003     External radiation treatment – 7 weeks

Suggestions:
1. Individual tracking of PSA
2. Research extensively
3. Become the ‘captain’ of your own treatment; others are navigators
4. Keep accurate medical records
5. Involve your loved ones, especially your spouse or companion, in your journey.

Additional ways I care for myself:
1. Exercise
2. Favorable nutrition
3. Become involved with support groups
4. Notify friends and family/ask for help
5. Prayer and spiritual support

Patient’s Present Status
PSA has held at 0.4 for over a year. I believe that this may be helped by taking soy isoflavones. If the PSA rises again, my next option would be some sort of hormonal therapy. In the meantime, my spouse and I are leading a very active life—biking extensively, social with family and friends, traveling, etc. LIFE IS GOOD!

Peer Recommendations

Be aware of your family medical history. If current tests are negative, continue to be vigilant about testing and self-care.

Be the ‘captain’ of your own treatment. Others are navigators.

Involve your loved ones, especially your spouse or companion, in your journey.

The medical information and procedures contained in this booklet 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.
Additional Resources

ORGANIZATIONS

American Urological Association Foundation
300 W. Pratt Street, Suite 401
Baltimore, MD 21201
Phone: 401-727-2908 / 1-800-828-7866
URL: formerly www.afud.org
Now: www.auanet.org
National organization focused on prevention and cure of urologic disease.

Prostate Cancer Foundation
1250 Fourth St., Suite 360
Santa Monica, CA 90401
Phone: 310-570-4700
Fax: 310 570-4701
URL: www.prostatecancerfoundation.org
Dedicated to a cure for Prostate Cancer by supporting research and treatment.

National Prostate Cancer Coalition (NPCC)
1158 Fifteenth Street, NW
Washington, DC 20005
Phone: 202- 463-9455
URL: www.4npcc.org
Email: info@4npcc.org
A coalition of organizations advocating for increased research funding.

Prostate Cancer Education Council
5299 DTC Blvd., Suite 345
Greenwood Village, CO 80111
Phone: 303-316-4685
Toll Free: 866-477-6788
Fax: 303-320-3835
URL: www.pcaiw.com/newsite/pcec/
Offering free or low cost prostate cancer screenings. Education about the prevalence of prostate cancer, the importance of early detection and available treatment options.

Prostate Cancer Research Institute (PCRI)
5777 W. Century Blvd. Suite 885
Los Angeles, CA 90045
Phone: (310) 743-2116
Fax (310) 743-2113
Helpline: (310) 743-2110
URL: www.prostate-cancer.org
Email: PCRI@ prostate-cancer.org
Education, prevention, treatment, research and improving present level of care.

Prostate Cancer Research Foundation of Canada
1262 Don Mills Road - Suite 1-F
Toronto, ON M3B 2W7 Canada
Phone: 416- 441-2131
Fax: 416-441-2325
URL: www.prostatecancer.on.ca
Email: info@prostatecancer.on.ca
Funds research and supports patient support groups.

SITES

Health Talk
Providing the latest information and access to trusted experts on advanced treatments & disease management. www.healthtalk.com

Cancer News on The Net
Bringing patients and their families the latest information on cancer diagnosis, treatment and prevention. www.cancernews.com

CancerFacts.com
Personalized information for patients, families, and caregivers, to help people make informed treatment decisions. www.cancerfacts.com

American Medical Association (AMA)
Prostate cancer specific information from AMA. www.ama-assn.org/ insight/spec_con/prostate/prostat2.htm

Doctor's Guide to the Internet
A resource for health professionals. www.docguide.com

Medical World Search
Search for information on medical topics. www.mwsearch.com

HealthSeek.com
A commercial health information guide. www.healthseek.com/

OncoLink
University of Pennsylvania site with extensive resources. Topics include screening, risk factors & pain management. www.oncolink.com

Remember:
Information is changing constantly. Some books and websites may contain information that is contradictory. Don't rely on only one source. Do your research and use your head. Always ask yourself, “Does this make sense?”
Additional Resources

SITES (continued)

**Oncology.com**
Complete, up-to-date source of cancer news and info for patients, health professionals and the cancer community.
www.oncology.com

**Prostate Cancer Information and Resources**
Includes drug information; discussion groups and newsgroups; fact sheets; and frequently asked questions.
www.pslgroup.com

**WebMD**
Interactive health information with a section devoted to prostate cancer.
www.webmd.com

**Dr. Koop.com**
An interactive health information site geared to the consumer.
www.drkoop.com

**Cryocare PCA**
Information about cryosurgery, a procedure that kills prostate cancer by freezing the cancerous cells.
www.cryocarepca.org

**PSA Rising Magazine**
www.psa-rising.com

PUBLICATIONS & VIDEOS

**A Primer for Prostate Cancer – The Empowered Patient’s Guide**
By: Stephen B. Strum, MD and Donna Pogliano
Publisher: Life Extension Foundation
ISBN: 0-9658777-6-0

**His Prostate and Me - A Couple Deals with Prostate Cancer**
By: Desiree Lyon Howe
Publisher: Winedale Publishing
ISBN: 0-9701525-7-4

**The Best Options for Diagnosing and Treating Prostate Cancer: Based on Research, Clinical Trials, and Scientific and Investigational Studies**
By: James Lewis Jr., PhD
Publisher: Health Education Literary Pub
ISBN: 1883257042

**Updated Guidelines for Surviving Prostate Cancer**
By: E. Roy Berger, MD, FACP and James Lewis, Jr., PhD
Publisher: Authorhouse
ISBN: 1410791297

By: Charles E. (Snuffy) Myers, Jr., M.D. Sara Sgarlat Steck, R.T. and Rose Sgarlat Myers, PT., Ph.D.
Publisher: Rivanna Health Publications
URL: www.prostateforum.com/nutrition.htm
ISBN: 096761290X

**Man To Man: Surviving Prostate Cancer**
By: Michael Korda, Publisher: Vintage
ISBN: 0679781234

**Dr. Katz’s Guide to Prostate Health: From Conventional to Holistic Therapies**
By: Aaron E. Katz, M.D.
Publisher: Freedom Press (CA)
ISBN: 1893910377

**My Prostate and Me: Dealing With Prostate Cancer**
By: William Martin, Ph.D. and Peter T. Scardino, M.D.
Publisher: Addison Books, ISBN: 1569778884

By Patrick C. Walsh, M.D. and Janet Worthington

**Prostate Cancer: A Non-Surgical Perspective**
By: Kent Wallner, MD Publisher: SmartMedicine Press
ISBN: 0964899108

**The Prostate Cancer Answer Book: An Unbiased Guide to Treatment Choices**
By Marion E. Morra, Eve Potts (Contributor), Hilda R. Muinos and Vincent De Vita

**The Prostate Cancer Sourcebook: How to Make Informed Treatment Choices**
By: Marcus H. Loo, M.D. and Marian Betancourt
Publisher: John Wiley & Sons, ISBN: 0471159271

**A Revolutionary Approach To Prostate Cancer: Treatment Options Doctors & Survivors Share Their Knowledge**
By: Aubrey Pilgrim Publisher: Sterling House ISBN: 11563150867
www.prostatepointers.org/prostate/lay/apilgrim/ (viewable online)

**That Black Men Might Live: My Fight Against Prostate Cancer**
By: Reverend Charles Williams, Vernon A. Williams, Charles Richard Williams
Publisher: Hilton Publishing; (November 1, 2003)
ISBN: 0971606730
Additional Resources

The ABC's of Nutrition & Supplements for Prostate Cancer
By: Mark A. Moyad
Publisher: Sleeping Bear Press, ISBN: 1886947694

100 Questions & Answers About Prostate Cancer
By: Pamela Ellsworth M.D., John Healy M.D., Cliff Gill
Publisher: Jones and Bartlett Publishers
ISBN: 0-7637-2267-7

Humanizing Prostate Cancer: A Physician-Patient Perspective
By: Roger E. Schultz, M.D. Alex W. Oliver -Patient
Publisher: Brandylane Publishers, Inc.

The ABC's of Prostate Cancer: The Book That Could Save Your Life
By Joseph A. Oesterling, M.D. and Mark A. Moyad (Contributor)
Publisher: Madison Books, ISBN: 1568330979

The Complete Prostate Book: Every Man’s Guide
By: Lee Belshin, M.S.
Publisher: Prima Publishing, California, ISBN: 0761504478

Making the Prostate Therapy Decision
By Jeff Baggish, M.D.
Publisher: Lowell House
ISBN: 1565658698

Mayo Clinic on Prostate Health
By: David M. Barrett (Editor), Mayo Clinic
Publisher: Kensington Pub Corp
ISBN: 1893005038

Men, Women, and Prostate Cancer: A Medical & Psychological Guide for Women & the Men They Love
By: Barbara Rubin Wainrib, Ed.D., Sandra Haber, Ph.D., with Jack Maguire.
Publisher: New Harbinger Publications, Inc.
ISBN: 1572241829

The Patient's Guide to Prostate Cancer : An Expert's Successful Treatment Strategies and Options
By: Marc B. Garnick, MD
Publisher: Plume, ISBN: 0452274559

Prostate Cancer - revised edition
By: David G. Bostwick, M.D., Gregory T. MacLennan, M.D. and Thayne R. Larson, M.D.
For The American Cancer Society, Publisher: Villard Books
ISBN: 0375753192

Prostate Cancer: A Survivor's Guide
By: Don Kaltenbach with Tim Richards
Publisher: Seneca House Press
ISBN: 0964008823

The Prostate Cancer Protection Plan: The Foods, Supplements, and Drugs That Could Save Your Life
By Robert "Bob" Burns Arnot M.D.
Publisher: Little Brown & Company
ISBN: 0316051535

Prostate & Cancer: A Family Guide to Diagnosis, Treatment & Survival
By: Sheldon Marks, MD, Publisher: Fisher Books, LLC
ISBN: 1555612067

The Men's Club: How to Lose Your Prostate Without Losing Your Sense of Humor
By: Bert Gottlieb, Thomas J. Mawn, M.D.
Publisher: Pathfinder Publishers
ISBN: 0934793670

BASIC PCa VIDEOS

Prostate Cancer Video Review
Produced by: Time Life Medical Director: C. Everett Koop, MD

Take Charge: For men newly diagnosed with prostate cancer
Produced by: State of the Art, Inc.(18882752605)
ISBN:1881782085

WHAT NOW? Hope and options when experiencing a rising PSA, a recurrence of prostate cancer, or when prostate cancer is not responding to treatment.

This booklet was produced by:
Us TOO International Prostate Cancer Education & Support Network.

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Someone to talk to… who understands
Notes...