

A Primer on Prostate Cancer

Written and Compiled by Donna Pogliano



The Primer has evolved into a book called "A Primer on Prostate Cancer, The Empowered Patient's Guide, by Stephen B. Strum, MD, FACP and Donna Pogliano, available through web booksellers, at local libraries and bookstores and at the [website of the publisher](#).

(Part 1 of 2 parts)

This is a very basic resource for a man and his family if there has been a finding of elevated PSA (prostate specific antigen) levels in the blood, an abnormal digital rectal exam, or a recent diagnosis of prostate cancer.

This is not intended to be medical advice, nor is it intended to replace consultation with persons in the medical profession. It is intended to be used as a starting point to increase your knowledge regarding prostate cancer. This primer is not all-inclusive and new information continues to be available, so your own research may produce updated data.

If you are leaning toward a specific treatment, you will need to find specific information regarding the cure rates and possible side effects both physical and emotional, for that type of treatment. You will need to consult with your physician to determine if the treatment is appropriate for your stage and grade of prostate cancer. And you will need to discuss your diagnosis and your treatment plans with your loved ones.

You should also be sure to ask your doctor what back-up options are available in the event the therapy you are considering should fail. And after treatment, you will need to be vigilant about monitoring your PSA, probably for the rest of your life. Fortunately, we now have this simple test to monitor the disease and give early warning if it returns, allowing for more

and earlier treatment opportunities. There is no quick-fix solution to a diagnosis of prostate cancer, and there are difficulties in finding the fine line between which cancers are "in remission" and which may be "cured".

This document incorporates the input of a great many people, all of whom have been touched in some way by prostate cancer. Some are battling the disease; some are spouses or partners of men who are fighting prostate cancer. The contributors to this primer are subscribers to various e-mail discussion groups on prostate cancer. They routinely share their knowledge and support with others who are feeling bewildered, alone and frightened much the same as you may be feeling now.

COMMON DENOMINATORS

There are a few common denominators in all of the contributors' advice to the newly diagnosed. Those who have "been there, done that" universally recommend that you move beyond the panic with knowledge, because knowledge is power. And they universally recommend that you take your time, do your research and arrive at the best treatment decision for YOU and your family, based on the characteristics of your own health situation.

Prostate cancer is a "couple's disease." It not only affects the man, but his sexual partner and his other loved ones. Stress and depression are common consequences of dealing with the diagnosis, the treatment decision, the treatment itself, and the side effects of the treatment. If depression becomes severe and overwhelming, it is appropriate to seek professional help. People deal with life crises in their own ways. It is especially important during a bout with prostate cancer to be good to yourself and the people whom you care about and who care

about you, so you are united in the effort to overcome the disease. A focused, reasoned, and calm attitude will be an asset in dealing with the day-to-day pressures all of you will face.

Remember-if any treatment really doesn't feel right, it isn't. If any treatment feels right, it probably is. After you have studied all your options, trust your instincts along with the knowledge you have gained. Ask questions until you are satisfied.

Be realistic. If a man is not generally in good health, surgery may not be the best option. Surgery of any kind is hard, and recovery is easiest when a person is in good shape. If a man has bowel or bladder problems already, radiation of any kind may make them worse. Fortunately, for many patients, there are a number of local treatment options, including various forms of surgery, radiation therapy or cryosurgery and systemic hormone therapy or chemotherapies, or a combination of treatments. There are also treatments under investigation that are not yet approved for treatment of prostate cancer in the US, but that are being performed elsewhere.

Question your doctors thoroughly regarding what side effects any treatment you are considering may produce. Some side effects of treatment are temporary and some become permanent. There is variation between individuals depending on their physical condition, age and response to various treatment modalities. There are medications to help patients cope with bowel or bladder problems resulting from treatment, and a vast array of measures to cope with partial or even total impotence.

Be aware that some medical professionals tend to understate risks, and medical professionals tend to steer you in the direction of their specialty. Urologists tend to favor the surgical option while radiologists tend to favor radiology. At minimum, you should have consultations with both, and possibly with an oncologist, a cancer specialist, who would oversee all aspects of your treatment. Ideally, you should see a medical oncologist specializing in prostate cancer. Unfortunately, their numbers are few.

The goal of prostate cancer treatment, it is often said, is to be sure the patient lives long enough to die of something else. Many prostate cancers are slow growing. You don't need to

make a decision regarding how to deal with your disease in days or even weeks. Many patients take as long as a few months to look at their options. You will have time to talk to your family about the results of your research and discuss the implications of the side effects so you are sure to be prepared to deal with them, and to be sure you have the support you need.

CHOOSING A DOCTOR

Choosing a doctor is an important step toward making a treatment decision. Your choice of treatment and who will perform it is crucial in giving you the best outcome based on the information that your test results yield. Your choice of treatment needs to fit with your age, life expectancy, lifestyle, general health, and your expectations for future quality of life.

Patient references given by a doctor may direct you to their successes, not to their failures, so make every effort to verify any information you are given. This goes for information that doctors give you regarding various treatment modalities as well. Ask for documentation. Ask other patients who have been there and done that. Also, realize that the doctor who diagnoses your prostate cancer may not be the doctor who is your best choice for treatment. Once you decide on a treatment modality, it is time to search out the experts in that field.

Consider your priorities. It is not wise either to overtreat your disease based on fear of recurrence, nor to undertreat your disease based on fear of impotence or other side effects. Most people would agree that when ordering your priorities, staying alive is at the top of the list, keeping firmly in mind that dead men don't have erections either.

If you are uncomfortable with your doctor, switch doctors until you find one you trust, who will take the time to examine you properly, answer your questions, and address all of your concerns, physical and emotional. Be sure to write down your questions in advance of your appointment, so you can be assured of getting the most out of your consultations.

Take your partner, wife or a good friend with you to your appointments and consultations. No one should have to go through this experience alone. Doctors expect to see someone to act as support, and most are disappointed if a patient arrives at his appointments alone. Many times,

it is that supportive person that researches the options and questions the doctor. This is perfectly appropriate.

The results of primary treatment are closely linked to the expertise of the doctor performing the treatment, so selecting the very best doctor (an artist) for a given procedure will significantly increase the chance of success. An artist is going to have overall better outcomes both with eliminating the cancer and with limiting the side effects of treatment than a mediocre doctor, no matter which treatment modality is your choice. It is therefore of utmost importance to decide not only on a treatment choice, but to seek out the best doctor to perform the procedure.

RECORD-KEEPING

Some people tape record every office visit so they can review what was said later and not be pre-occupied with taking notes. To get the most value from this approach, it will be necessary to listen to the tape and take notes about what seems really important.

Be sure to get copies of the results of all the medical, surgical, diagnostic and therapeutic procedures that are done. Should you decide to change doctors later, this is valuable information. And you will need this information, in chronological order, to record items in your prostate cancer "digest," your own permanent record to be used as a supplement to your medical records in the event you choose to seek advice regarding your care and treatment from another source.

Notes regarding conversations with your doctors, medication and diet changes, anything that may be pertinent to your treatment should be part of your digest. Doctors who are experts in the field of prostate cancer volunteer their time on e-mail lists to patients with specific, complex problems. (See the Resource List later in this primer under "Helplines.") If you ever wish to use this service, the specifics of your case are most conveniently communicated by means of your prostate cancer digest. Keep the information in a safe place.

Seek out experts to perform your treatment. It is not unusual for patients to travel across the country to seek out the very best medical professionals, some of whom have performed thousands of successful procedures. These

people are considered "artists." You have a life. You deserve the best treatment.

Many will accept your insurance company's "reasonable and customary charges" limit as payment in full, or with only incidental out-of-pocket expense to you. Ask questions regarding this aspect of your treatment. Some procedures and medications are very expensive. You need to put your mind at ease up front regarding the financial burdens you may incur so that you can be free to focus on fighting your disease.

GATHERING INFORMATION

It will be of great benefit in researching your treatment options and seeking out support if you have e-mail and Internet access. If you were to put "prostate" into a search engine on the Internet, you would get more information than you would ever want. We have provided some of the available Web sites and support group Web sites in the Resource list [at end of document] for your convenience.

If you don't have computer access, you might want to visit your local library and see what computer resources they can offer. Most libraries now have computers for patron use and librarians who can help you find and print the information you are seeking, so you can read it later, and have it available for reference. Don't be afraid to ask for help. And don't be afraid to tell the librarian why you need the information. You may find that cancer has also touched that person, and they are willing to give compassion and help. Keeping your diagnosis a secret makes it much more difficult to deal with.

You have now inadvertently joined the fraternity of prostate cancer. You have a responsibility to yourself and your loved ones to get the best care and most information you can. And THEN, to become an advocate for more support for prostate cancer research, early detection, early cure, and to help mentor those who come after you as so many others have done. You are in VERY good company!

NUTS AND BOLTS

It is estimated that 50% of men over 50 and 70% of men over 70 have some form of prostate cancer. Some of these cancers are life threatening, but the majority will grow so slowly as to never be a threat to life, so more men will die "with" prostate cancer than "of" it. Some

men have such overwhelming health issues before being diagnosed with prostate cancer, that treatment is not indicated, or that palliative treatment is all that is necessary. The intention of palliative treatment is to help the patient deal with the pain and discomfort of the disease and is not intended to cure the disease.

However, prostate cancer can strike men in their 40's and 50's, and even as young as their 30's, and if life expectancy is more than ten years, more aggressive treatment is usually indicated. Family history of prostate cancer or breast cancer would suggest that regular PSA (prostate specific antigen) blood tests be started at age 35. For other men, screening should begin at age 40.

THE BASICS

The prostate gland is part of the endocrine system, a walnut-sized gland that sits between the bladder and the rectum at the bottom of the pelvis, surrounding the urethra. It adds vital nutrients and fluid to the sperm, and therefore local treatment for prostate cancer impacts upon a man's ability to father children. Because local therapies affect prostatic secretion, they also impact upon a man's sexuality, specifically affecting the quality of ejaculation and orgasm. Only men have prostate glands.

Cancer of the prostate gland is not contagious or sexually transmitted. It is generally accepted that there is a genetic link which increases risk of prostate cancer and that a diet high in saturated fat over many years can contribute to the development of prostate cancer.

There is now evidence that there is a hereditary link between prostate cancer and breast cancer (in women and in men). This genetic link makes it wise for a man diagnosed with prostate cancer to advise his progeny of both genders to undertake early and adequate screening for prostate cancer in his male children and for breast cancer in his female children.

Furthermore, the younger the blood relative is at the time of diagnosis of prostate cancer, the greater the risk to his male and female relatives, including children, siblings, cousins, nieces and nephews. Black men seem to have the highest prostate cancer incidence, followed by Hispanic men. The causal factors involved could be genetic, environmental, or a combination of factors and are being

investigated. Meanwhile, it would make sense for men in these groups to be vigilant about PSA testing and digital rectal exams (DRE's).

HOW DOES CANCER WORK?

Cancer is a disordered and abnormal cell growth. Cancer cells have lost the ability to network and communicate in the way that normal cells do, and can no longer function as intended in the overall framework of bodily chemistry. They also no longer die as they should, through normal cell death and replacement, and they grow beyond their normal borders. Eventually, they can overwhelm the system.

Some cancers are slow growing and not typically life-threatening. Some are aggressive, fast-growing cancers. There is a lot of variation. Doubling time and velocity can be calculated by you or your doctor to determine how fast the cancer is growing.

Prostate cancer confined within the gland itself is called "organ confined" prostate cancer. When prostate cancer has not penetrated the perimeter of the gland, referred to as the prostate "capsule" it is very treatable with curative intention. Options such as surgery or various forms of radiation typically result in ten or more years of being disease-free. Some people call that being in "remission." Most people call that "cured."

If the cancer spreads before local treatment can be undertaken, it usually has penetrated the capsule. After penetrating the capsule, it may spread also to the lymph nodes, seminal vesicles, adjacent bladder and then to the bone, most often to the spine, pelvis and ribs. Prostate cancer can also involve vital organs such as liver and lungs. When it reaches that advanced state, it usually has a fatal outcome.

DIAGNOSIS AND TESTING

A vast array of testing procedures is available to correctly assess the character and spread of any particular prostate cancer. Most patients will not need all the tests that are available, but most doctors will honor an informed patient's requests for any testing that seems reasonable. Some insurance companies or HMO's may not agree to pay for all the available tests.

It is vital that everything that can be known

about your cancer be discovered BEFORE you make a treatment decision. That way, you will have the confidence that the treatment you undertake will be the best choice of treatment for your particular situation. Many doctors will stress that with the current available treatment options, you have ONE chance at a cure if you have organ-confined disease. And they will not be responsible for making that choice for you, since you need to live with the consequences of your decision for the rest of your life.

THE PSA

The first test, used primarily as a screening procedure since 1990, is the PSA blood test. Blood is drawn and tested for the presence of "prostate specific antigen," a marker in the blood that indicates the presence and extent of cancer activity. PSA is actually an enzyme made by prostate tissue. Its purpose is to dissolve the proteins that cause semen to clump. Further investigation to determine if cancer is present is usually recommended if the PSA is over 4, and some doctors feel that 2.6 merits monitoring on a six-month basis to see if there is an upward trend. This will be discussed in more detail below.

Free PSA testing can easily be used to weed out some of the patients with PSA's above 4 that are not cancer-related. Free PSA testing (see further information later in this section) can rule out benign prostate hyperplasia (BPH), but not prostatitis.

At minimum, before undergoing a biopsy, you should have your PSA tested several times. There is considerable variation in test results depending on the lab and assay used, so you need several readings to arrive at an average. Refrain from ejaculation at least 48 hours before the blood draw, and do not do anything else that massages the gland for one week prior to the blood draw, such as using a bicycle or exercise bike, or riding a motorcycle. It is thought that these activities can temporarily raise your PSA, and could result in unnecessary concern or inappropriate testing based on distorted PSA results.

Some men with elevated PSA should routinely follow up with a Free PSA test to help rule out causal factors other than cancer. This is another type of blood test which might avoid needless biopsies if used more regularly. However, this test is only reliable for PSA's of between 4 and

10. Recent studies indicate the lower level of reliability may be 2.5.

Also, after the first elevated PSA and before a biopsy, some experts recommend that you be tested for prostatitis, or inflammation of the prostate. If this condition is found, it can be treated with antibiotics, such as Cipro, usually prescribed for a month or more. Prostatitis can be a non-cancerous cause of an elevated PSA. Be sure to wait at least six weeks after the condition is cleared up and medication is discontinued before rechecking the PSA. Benign Prostate Hyperplasia (BPH) is a result of an enlargement of the prostate, which also elevates PSA levels. Symptoms can mimic those found in some cancers, but this is a treatable, non-cancerous condition.

An often-unused approach to PSA evaluation relates to what the PSA levels are doing over time. Malignant processes relate to persistent cell growth and production of specific proteins. With prostate cancer, this would relate to PSA production. If the rate of doubling of the PSA (PSA doubling time or PSADT) or the rate of increase in PSA (PSA velocity or PSAV) is abnormal, then prostate cancer is more likely present than not. PSADT should be longer than ten years to rule in a benign process. PSA velocity should be less than 0.75 ng/ml/year on the test results to rule out prostate cancer. These are adjunctive tests and are not absolute criteria for or against malignancy. However, they are valuable tools and their principles apply to all malignancies.

DIGITAL RECTAL EXAM

Digital rectal exam (DRE) is used in combination with PSA testing to determine if there is any evidence of a palpable tumor. The doctor will insert a gloved finger inside the rectum to feel the gland. This isn't as bad as it sounds. It may help you to keep in mind that women are routinely poked, pummeled and invaded in an effort to maintain good health. You can deal with this.

The digital rectal exam (DRE) will be a factor in establishing the Clinical Stage of your cancer, which will help to assess your situation and enable you to describe your condition in a way that others who know what staging means will understand. The TNM system is used internationally at this time to describe the cancer and its spread. "T" describes the tumor,

whether or not it can be felt, how large it is and whether it occupies one or both sides of the prostate. "N" stands for nodes and describes whether or not the cancer has spread to the lymph nodes. "M" stands for metastasis, and indicates whether or not the cancer has spread to other organs or tissues. A full description of TNM staging designations is available on the Internet. See the Resource List later in this primer under "Quick Reference".

FREE PSA

If PSA is between 4 and 10, requesting a test for "free PSA" also termed fPSA or PSA II might help to rule out cancer as the cause. Clarifying the reason for the elevation could spare the patient the intrusion of a biopsy. This test is a different type of PSA blood test, which can be used to help rule out non-cancerous enlargement of the prostate gland, called BPH or benign prostatic hyperplasia. BPH can also cause elevated PSA readings. This test yields a "% free PSA" number. The lower the number, the more likely you are to have prostate cancer. A high limit of 25 or more would indicate that the man might not have cancer. This test should be done routinely if PSA is elevated between 4 and 10, before making a decision regarding undergoing a biopsy.

BIOPSY OF THE PROSTATE

If a biopsy is done, it should consist of at least six needle sticks, placed in separate, well-labeled vials so the pathologist can draw conclusions based on the locations from which the samples were taken. Some studies indicate that a ten or twelve needle biopsy approach shows an overall increase in cancer detection of as much as 35% and is recommended.

The biopsy results will yield the Gleason grades. This is a subjective analysis by a pathologist of how the prostate cancer appears in the sample (biopsies) as compared to normal cells. The number will be between 1 and 5 for each Gleason grade, the higher number indicating a more aggressive cancer. The Gleason "score" or "sum" will be derived from adding the two grades. The first number indicates the predominant grade; the second number is the second most predominant grade. The predominant Gleason grade has to be at least 51% of the total picture seen under the microscope. The secondary Gleason grade has

to be at least 5% of this same picture. This is stated as, for example, (3,3), which is the most common Gleason score. A Gleason score of (3,4) indicates that anywhere from 51% to 95% of the specimen is Gleason grade 3 disease and that anywhere from 5% to 49% of the specimen has a secondary pattern of Gleason grade 4 disease. Gleason grades 4 and 5 disease are important NEGATIVE prognostic indicators for the extent of disease and the clinical course of prostate cancer.

Tissue samples taken during biopsies are preserved and retained, making it possible to send the samples to an expert prostate cancer pathologist for review and confirmation. Experts in assessing prostate cancer biopsies are available at specific labs, such as UroCor, Inc. and Dianon Laboratories, and at certain major medical centers. Samples from all over the country can be sent to these artists for "second opinions". Don't be afraid to ask for this additional assurance that your Gleason is correct, because this will be a MAJOR factor in your decision-making process. If your Gleason is inaccurate, you may overtreat or undertreat your cancer based on erroneous information! Refer to the Resource list [end of document] under "Quick Reference" for a list of expert pathologists who can be consulted to confirm your Gleason score.

PAP

You should request a PAP (Prostatic Acid Phosphatase) test after your diagnosis. This can help determine if the cancer is most likely organ confined or not. This blood test measures an enzyme in the blood. A PAP of 3.0 or higher is cause for concern. Since there is no universally accepted standard regarding stated range of PAP at this time, you should be sure that your test is always sent to the same lab so that you can be assured of consistent results if you are tracking your PAP over time.

Persistently elevated levels are considered possible evidence of metastases (spread of the cancer). It is inconclusive to rule out spread beyond the capsule, the shell of soft tissue that covers the prostate, because only 75% of patients with metastases have an elevated PAP. However, if your PAP is 3.0 or higher, most doctors do not consider you a good candidate for surgery, since the risk of PSA recurrence (PSAR) is four times higher when this level of PAP is found.

Note that PAP is not particularly useful in predicting local spread to surgical margins of the gland. But it is one more indicator that may be useful in predicting which patients are likely to have a relapse after surgery. If PAP is elevated, hormone therapy may be prescribed to halt or slow the spread of the cancer. PAP like PSA should not be done for at least five weeks after prostate biopsies. Ideally, both PSA and PAP should not be done unless 48 hours has elapsed since any ejaculation.

PROSTASCINT

ProstaScint is a relatively new technique in which a radioisotope is injected into the bloodstream. The isotope attaches itself to the cancer, then a gamma-ray camera is used to locate evidence of cancer, if any, in your body. This test is not 100% accurate, but it can be valuable in combination with other testing. There are false positives. The ProstaScint may indicate node involvement, in which case, treatment options would be directed away from local therapy such as surgery, radiation therapy or cryotherapy.

ProstaScint is used most often in cases of recurrence of prostate cancer after local treatment of the gland or in patients with high-risk profiles for non-organ confined prostate cancer at diagnosis. The patient needs to be made aware that this test uses mouse antibodies. Some investigational clinical trials exclude anyone who has had a ProstaScint test for that reason.

ENDORECTAL MRI

Endo-rectal MRI is a useful tool in establishing evidence of extra-capsular extension, particularly if it incorporates spectroscopy. This technique is far superior to a routine pelvic MRI and is associated with a 75% to 90% accuracy rate when there is agreement between both modalities of imaging. This test is used to help determine the probability of organ-confined disease. This test is also useful in determining spread to seminal vesicles and regional nodes. It can also be extremely useful in detecting the site of prostate cancer in men suspected of having disease but eluding diagnosis on routine ultrasound guided biopsies.

OTHER TESTS

DNA ploidy is another test that may be recommended to determine the nature of the cancer: its aggressiveness and its responsiveness to androgen deprivation therapies. Ploidy is a term used to describe the chromosome content of the cell population of a tumor. This would be particularly of interest to patients involved in hormone therapy to try to determine the likelihood of the effectiveness of the treatment. Diploid cells have normal chromosome pairs and normal DNA. Diploid cancer cells tend to grow slowly and respond well to hormone therapy. Aneuploid cells have abnormal numbers of sets of chromosomes. Aneuploid cancer cells tend not to respond as well to hormone therapy and to be more aggressive. Aneuploid tumors are more often associated with high Gleason score prostate cancer (8-10) and non-organ confined prostate cancer.

Bone scans are often done to determine if there is any evidence of metastases to the bone, and should routinely be done if confirmed PSA is over 10. In early stage cancers, this is very rare, so don't panic if your doctor recommends a bone scan prior to embarking on treatment. It is a precautionary measure and commonly done. Depending on your PSA and Gleason, your doctor may even tell you that it is likely it will come back negative or show signs of arthritis, in which case x-rays may be needed as confirmation. Be sure to tell the doctor of any past injuries to the bones that may show up as spots on the bone scan. Your physician may decide to forego a bone scan if your PSA is 10 or less and your Gleason score, validated by an expert, is 6 or less.

CT scans may or may not be indicated, depending on the results of other testing. If the cancer appears to be advanced, this can be one more tool to determine what your treatment options are. Advanced prostate cancer is usually associated with high PSA readings of 50 or higher and often Gleason scores of 8-10. CT scanning is a serious waste of healthcare dollars when used in the workup of 90% of men with prostate cancer. It is highly insensitive in detecting disease in the lymph nodes and valueless in most patients in detecting extra-prostatic extension such as capsular penetration or seminal vesicle involvement. In the setting of high PSA and/or high Gleason scores, a CT scan may disclose lymph nodes that are greater than

1.0 centimeters in diameter. When such nodes are found they are associated with a specificity for prostate cancer of almost 100%.

CGA testing measures the blood levels of Chromogranin A. This test is used to help identify patients with an aggressive form of prostate cancer and to help track their response to treatment. In such patients, the CGA elevation should be shown to be progressive and not just sporadically elevated. CGA elevations in conjunction with elevations in other markers such as NSE (Neuron-Specific Enolase) or CEA (CarcinoEmbryonic Agent) are cause for serious concern of mutated aggressive prostate cancer. Always put these findings in context with the rest of the clinical and pathological picture.

After the results of testing have been obtained, and prior to a treatment decision, you and your doctor should consult the Partin Tables to determine the probability of organ-confined disease, probability of spread to the seminal vesicles, and probability of lymph node involvement. See further discussion of the Partin tables in the section of this primer under Radiation Therapy, Permanent Seed Implants.

More information on Markers and Tests for Prostate Cancer is available on the Internet. See the Resource List later in this primer under "Quick Reference".

TREATMENT OPTIONS

SURGERY

Radical prostatectomy (RP) is the surgical removal of the prostate. It has a long track record. It is not effective as curative therapy if there is spread of the cancer beyond the borders of the surgically removed specimen. Most commonly, lymph node biopsy is done early during the radical prostatectomy procedure, and if evidence of spread to the lymph nodes is detected, the surgery may be aborted in favor of other treatment options, since the procedure is not curative. However, there are convincing studies from the Mayo clinic showing that patients undergoing radical prostatectomy with diploid tumor do exceptionally well with androgen deprivation therapy despite lymph node metastases and the RP affords significant benefit in such patients. There are also studies from Duke University that

indicate that RP in the setting of no more than two lymph nodes involved confers a significant survival advantage.

Surgery affords the benefit of allowing assessment of the size, distribution and aggressiveness of the cancer by doing a full pathological exam of the removed gland and seminal vesicles along with lymph node sampling, as opposed to the tiny samples obtained by biopsy. Although this doesn't give a full representation of the extent of the disease (distant metastases, for example) it does provide more complete information than other treatments can.

Surgery may result in temporary or permanent incontinence and impotence, but some patients accept that risk in the belief that the procedure will result in the most favorable cure rate and thus, they will have peace of mind for their future. RP is technically difficult surgery and requires the selection of an artist to achieve outstanding results and to minimize adverse effects.

Both surgery and radiation therapy destroy the prostate gland resulting in dry orgasms. There is no ejaculate because the prostate can no longer produce the fluid that it produced when it was intact.

Nerve-sparing surgery is possible in some, but not all cases and cannot be determined prior to the procedure. The doctor's goal in surgery is to remove all the cancer, not to preserve erectile ability. If one or more nerves are spared, some men are able to achieve erections unassisted or by use of Viagra or other similar drugs being tested and approved for treatment of erectile dysfunction. Probability of regaining erectile ability with or without Viagra after surgery increases if the patient is relatively young (50 and under), if he had no erectile difficulties prior to his surgery, and if he was sexually active before the surgery.

If Viagra doesn't work or both nerves responsible for conducting the impulses from the brain resulting in erections are removed, options include injections of drugs into the penis (again, not as bad as it sounds and favored by many over other options), and vacuum erectile devices (VED's) which manually draw blood into the penis resulting in an erection. Some men have surgery to install penile implants if they are not comfortable with the other options.

Incontinence is due to surgical involvement of the muscles that control urination. Urinary incontinence may be temporary or permanent. In general, younger patients recover full continence faster, while older patients need to be just that-patient. Stress incontinence, releasing urine involuntarily while lifting, coughing or sneezing, can be a lingering side effect, particularly in older men. Incontinence as a result of RP is related to the skill of the urologist doing the surgery.

Exercises, called Kegel exercises, are done to help retrain the muscles responsible for containing and releasing urine at will. Other options for long-term incontinence include drug therapies, physical therapy, biofeedback and other options, including surgical implantation of an artificial urinary sphincter or AUS.

In general, whatever the problem, there is usually some treatment option available to you. And in the event of recurrence, you have radiation treatment and/or hormone treatment to fall back on. However, the fewer the intrusions into the human body the better. Therefore, it is important to try to properly select the patient for a treatment that is most appropriate to him and to prepare the patient for the therapy while always choosing an artist to perform the procedure.

RADIATION THERAPY

Radiation therapy (RT) is another commonly used treatment for prostate cancer. There are several commonly used forms.

Brachytherapy

The word "brachytherapy" comes from the Greek words "brachy" meaning "close by" and "therapia", in this instance, referring to a radioactive source applied in or near the tumor.

Permanent Seed Implants (SI) or High Dose Rate Temporary Brachytherapy (HDR)

Brachytherapy is available in the two forms mentioned above. Treatment by permanent seed implant (SI) involves injecting a number of radioactive seeds into the prostate gland. The seeds consist of radioactive material encased in a titanium shell smaller than a grain of rice. The radioactive material can be iodine, with a half-life of two months, or palladium, with a half-life

of two weeks. Your doctor will help make the determination as to which is most appropriate for your cancer and will determine how many seeds you need to adequately treat the size of your prostate gland. The smaller the gland size, the fewer seeds you will need to adequately treat the entire gland.

The seeds are inserted through hollow needles, under anesthesia, through the perineum (the space between the scrotum and the anus). This is usually "day surgery" or done as an outpatient procedure and normally does not require an overnight hospital stay. Some doctors place seeds in areas outside the prostate, such as the seminal vesicles, if they are considered to be at high risk for cancer spread. Sometimes external beam radiation in addition to seeding is necessary to kill any cancer thought to have escaped the capsule and still be contained within the pelvic region.

A major disadvantage of this form of treatment is inability through the procedure itself to obtain evidence as to whether the cancer has spread beyond the capsule to an area that the radiation from the seeds cannot reach. Proper testing prior to the procedure is therefore very important. In addition, patients considering either form of brachytherapy or considering surgery need to refer to the Partin Tables and Bluestein predictions to obtain their percentage for risk of extra-capsular penetration and lymph node involvement. You or your doctor can determine these figures. The Partin Tables are also available on the Internet. See the Resource List later in this primer under "Quick Reference." The Partin Tables were compiled by analyzing prostate glands removed during surgery to determine the spread to lymph nodes and seminal vesicles.

Treatment by seed implantation can result in bowel and bladder problems, usually temporary and treatable with medication. The urethra goes through the prostate gland and the insertion of the seeds or wires can cause the prostate gland to swell, which can cause in varying degrees, restriction of the urine flow from the bladder. In severe cases a catheter may be used to overcome difficulties in urination that arise as a result of brachytherapy. Self-catheterization kits are available for home use if urinary retention problems persist for an extended period of time.

The procedure has the advantage of being inherently nerve-sparing, which means that

Viagra or new medications that act similarly will produce erections in most patients. Incidence of at least partial impotence seems higher than usually disclosed, especially in patients 70 and older. Longer term follow-up of patients having brachytherapy and its effect on erectile function is needed.

Many patients experience a rising PSA at some time after having brachytherapy. The average time to this PSA "bump" is 18 months. This phenomenon is thought to be the result of radiation-induced prostatitis, a reasonable explanation for this bump in PSA. This stressful event can be avoided if patients know that a rise in PSA may not necessarily indicate a recurrence of the cancer, pending the timing of the PSA rise and the history of having received brachytherapy.

If however, testing indicates the treatment has failed, traditionally the salvage treatment is hormone therapy, but High Dose Rate (HDR) temporary brachytherapy is now also being used for failed treatment by permanent seed implants. Surgery after radiation is seldom done because of the high incidence of severe complications. Many men prefer to avoid the increased risk of complications and elect hormonal therapy instead. Cryotherapy (freezing the prostate) is now being used by some as a salvage therapy after failure of primary treatment.

High Dose Rate Temporary Brachytherapy (HDR)

High dose rate (HDR) brachytherapy is the other form of brachytherapy. Unlike permanent seed implants, no "seeds" remain in the prostate after treatment. The procedure usually involves an inpatient hospital stay of about two days. Tiny plastic catheters (hollow tubes) are inserted into the prostate gland and the tumor. The patient is then placed on a very high powered CAT scan to aid in refining the position of the catheters to ensure there are no cold spots. A computer-controlled machine then pushes a single highly radioactive iridium wire into the catheters one by one. The wires are left there for a few seconds, then removed.

The computer can control the length of time a single wire remains in the catheter and therefore precise dosages to different areas of the prostate and the tumor are possible. The tumor itself can be treated with a higher dose of

radiation, while sparing healthy tissue and surrounding organs, thus bowel and bladder complications are more likely to be minimized. Patients report that no urinary catheter was necessary after this treatment.

The goal of this procedure is to destroy the cancer quickly, with higher doses of radiation than could be permanently implanted. Ideally, placement of the radiation is very precise, leaving no cold spots. HDR, in use for over ten years, is gaining acceptance as a highly effective alternative to conventional permanent seed implants. It is presently done in just over a dozen places in the United States. (See the Resource List.) The equipment and training are very expensive, but the cost of treatment is competitive.

HDR is usually combined with external beam radiation therapy to destroy cancer that may have escaped the capsule yet still remains within the pelvic region.

External Beam Radiation Therapy

Another type of radiation is external beam radiation therapy (EBRT). Some radiation oncologists use EBRT in conjunction with treatments to the pelvis in an attempt to cure prostate cancer that is not organ confined. Full pelvis EBRT seems ineffective in curing the cancer and may result in bowel and bladder problems due to radiation being poorly directed and affecting healthy tissue.

However, there is new technology in the field of external beam radiation. 3-D conformal beam radiation therapy (3D CRT) comes highly recommended and is widely used, particularly in conjunction with brachytherapy to be sure any cancer which has spread to the immediate area surrounding the gland is also killed. In this procedure, marks are made on the body, or a custom-made body mold is made for positioning the patient during the treatments to help insure that the radiation is delivered precisely to the intended area. Various other techniques are employed in modern beam radiation treatment to control for such factors as the movement of the prostate and variations caused by fullness of the bladder or bowel.

Intensity Modulated Radiation Therapy (IMRT) is another major advance in treating prostate cancer that minimizes radiation to the normal tissues. IMRT uses sophisticated computer

planning that allows the radiation oncologist to designate how much RT he wants administered to both malignant and normal tissues. The IMRT hardware allows variation of the dose of RT while the equipment moves around the patient to fulfill the equation determined by the computer. This is a serious advance in the technology of RT and should be the basis for all radiation in the near future. See the July, 2000 issue of Insights (PCRI) for a full discussion of IMRT. (See the Resource List under General Information.)

Proton Beam Therapy

Proton beam therapy is a lesser-known radiation therapy done at only a few centers in the United States. It does not currently have a long track record, so long-term cure rates are uncertain. It uses the proton instead of the photon for the treating particle. Protons have the ability to be more sharply focused and their energies fall more within the target tissue (the prostate and seminal vesicles) than outside the gland. Comparison studies of proton beam vs. 3D CRT or IMRT have not yet been done.

ANDROGEN DEPRIVATION THERAPY (Hormone Therapy)

Hormone therapy is recommended for patients whose prostate gland is too large to be effectively treated with EBRT, brachytherapy or cryosurgery, and needs to be reduced in size before these procedures can be performed. Hormone therapy can thus make these local therapies more effective and reduce their side effects.

Hormone therapy is sometimes used in conjunction with various radiation therapies for the purpose of limiting testosterone production and reducing tumor volume, since this will increase the effectiveness of RT and yield a higher disease-free rate. EBRT of any kind, brachytherapy and cryotherapy are all volume-dependent treatment modalities. If there is too much tumor volume, they will not be effective.

Some patients who feel the need to buy time for one reason or another-to research their options for treatment or because of some other pressing life issue that prevents immediate treatment may initiate ADT. ADT is sometimes used for this purpose, but it may not be necessary and may preclude treatment at some centers.

For men with advanced prostate cancer, ADT is the only currently recognized effective treatment option. For some men with distant metastases, this therapy can work for many years. Intermittent androgen deprivation therapy can have a positive impact on quality of life because in off cycles, the patient gets a break from the side effects of treatment.

This therapy typically uses drugs to eliminate the production of testosterone by the testes, thus removing the nourishment to the cancer. Some patients choose this therapy as primary treatment because they are unwilling to undergo a more invasive treatment for health reasons, due to advanced age, or other factors. However, be aware that the side effects of ADT are many and varied, although not all patients experience all of the possible side effects. One common side effect of long-term ADT is osteoporosis, which compromises the integrity of the bones and can result in fractures, bone pain and shortening of height due to compression fractures of the spinal vertebral bodies.

Younger men typically wish to avoid ADT because it results in decreased libido (sex drive). However, some informed younger men are using hormone therapy as primary treatment, with the idea that there are many fall-back options if it is not effective. If the disease is brought under control, a patient may be able to stop the medication intermittently for long periods and would still have his prostate. Once the prostate is destroyed, orgasms are "dry", that is, without ejaculate. Some men report that the sexual experience is thus permanently diminished for them.

Effects of temporary ADT for a short term (less than two years) are typically reversible once testosterone production is naturally resumed by the body, or resumed by introduction of testosterone drug therapies.

Cancers that have spread to the bone can be dramatically halted or slowed by ADT resulting in almost immediate pain relief. Testosterone production can also be halted by surgical removal of the testicles (orchiectomy) and by drug intervention to block male hormones (androgens) produced by the adrenal glands as well as the testicles. Agents like Ketoconazole (Nizoral) have this ability.

Orchiectomy is a surgical procedure in which the testes are removed from the scrotum surgically, so the testosterone they produce is unavailable. This is an irreversible method of depriving the body of testosterone. It is sometimes done for reasons of economy, because the drugs involved in hormone therapy are very expensive. Both orchiectomy and drug ADT are capable of reducing the testosterone to castrate level.

The use of ADT is complex and controversial. The options for specific drugs to be used alone or in combination need to be thoroughly discussed with your doctor. If you are a candidate for this therapy, it is recommended that you research all of your options very carefully.

WATCHFUL WAITING

Watchful Waiting (WW) is an option for some cancers. A cancer that appears to be slow growing and organ confined may require no local treatment for some time, if ever.

Some patients feel that they can preserve their quality of life by avoiding more aggressive treatment and proper testing can help determine if this is an option for any specific case.

Watchful waiting does not mean doing nothing. It implies that the patient is embarking on a regimen of diet and exercise best suited to his condition in consultation with his doctor. See the Resource List later in this primer under "Diet & Lifestyle" for specific information on what the experts recommend in this regard and what current research indicates. Some patients using watchful waiting are using herbal supplements, meditation, exercise, prayer, humor and a variety of other methods in concert, in an attempt to control the disease. It is wise to closely monitor the cancer in the event that more aggressive treatment seems indicated.

CRYOTHERAPY

Cryotherapy is a lesser-known therapy that is gaining some acceptance. Hollow needles are inserted through the perineum and liquid nitrogen is used to freeze the prostate and destroy the cancer. This therapy is being used as a salvage procedure in the event of recurrent cancer after EBRT or brachytherapy has failed.

However, it is a reasonable primary therapy for prostate cancer that is organ confined or that is associated with minimal disease extension into the capsule. This therapy mandates the choice of an artist.

MICROWAVE THERMOTHERAPY

New on the horizon is microwave thermotherapy, just recently approved by the Federal Drug Administration for use in the U.S., offering an alternative for those men who are not good candidates for surgery. This therapy heats the gland, thus killing the cancer. There are also no established cure rates as yet for this relatively new treatment.

TREATMENTS ON THE HORIZON

There is currently no "magic bullet" to cure prostate cancer. However, research and clinical trials are proceeding to develop medications that will search out and destroy cancer cells in the body by various methods. In the future, some of these therapies may gain approval by the Federal Drug Administration and be put into use by the general public.

Aptosyn (Exisulind) is a drug that has been successfully used in clinical trials and is undergoing further testing. It theoretically directs precancerous and cancerous tissue to self-destruct without harming healthy tissue. This is one of a number of "smart bomb" drugs in clinical trials. The FDA is expected to give approval on this drug manufactured by Cell Pathways, Inc.

There are also numerous other drugs under clinical testing that may hold promise for future treatment. Anti-angiogenesis drugs (Endostatin, for example) may eventually be available to "turn off the switch" in molecules that signal blood vessels to develop and nourish tumors. Without nutrients, the tumor shrinks.

Vaccines are also being tested which use the body's own immune system to cause death of cancer cells.

Chemotherapy is used in the treatment of prostate cancer in advanced stage disease in the hope of slowing the growth of the cancer and prolonging life. There is an experimental treatment currently being investigated, using imaging with vitamin B-12 to detect tumors. This could be used as a vehicle to destroy

tumors by attaching a lethal anti-tumor agent to vitamin B-12, which tumors use to build their network of cells and blood vessels. Tumors are detected by use of vitamin B-12 because of higher B-12 concentrations than in normal tissue, since tumors require more of this vitamin than normal tissues require.

CLINICAL TRIALS

Drugs being tested and other experimental therapies are the subject of clinical trials. Clinical trials are not usually a preferred primary treatment option. But for patients who feel they have few options left, clinical trials may be appropriate.

These trials are done in Phases, with Phase I being the most experimental, to determine proper dosages. Phase II is usually a trial done on a limited number of patients, once optimum dosage is determined. Phase III is usually a widespread test population which precedes the application for approval by the Federal Drug Administration to make the drug or treatment available to the general public.

If you are considering becoming involved in a clinical trial, you need to research thoroughly and ask questions. Will you get the drug or will you be part of a double-blind study in which a control group does not get the medication or treatment? What will the side-effects likely be? Will you be able to leave the test at any time if you choose? Will you be eliminated from the test under certain conditions? Do you fit the criteria for involvement in the test you are considering?

The costs of clinical trials are not currently covered by most insurance plans, but new legislation may bring changes in this policy, making participation in clinical trials possible for more patients, resulting in faster progress in developing new medications and treatments.

RESOURCE LIST

Books, Web sites and e-mail mailing lists

The information provided in this Resource List is included in an attempt to provide prostate cancer patients and those who love them with help in their search for information about their disease. This list in no way is intended to be all-inclusive and it certainly could never exhaust all the information available on any particular

topic. Some of the resources included are commercial sources, since the profit motive in many cases has provided the impetus for the existence of the material.

It must be recognized that the people responsible for providing this Primer on Prostate Cancer and its informational content have no financial interest or connection with any person, product or institution included in the Resource List, nor are they endorsing any particular product, institution, person or treatment modality. Inclusion of a resource does not imply or constitute any endorsement, and conversely, omission of any product, institution, person or other resource does not imply or constitute a negative endorsement.

BASIC INFORMATION:

"Prostate & Cancer, A Family Guide to Diagnosis, Treatment and Survival" by Sheldon Marks, M.D., specifically recommended for its good organization and completeness. This book may be a little outdated in terms of newer treatments such as high dose temporary radiation therapy and cryotherapy, since these procedures are in more widespread use since the book came out, but it is still a valuable resource.

A book that can be read on line [A Revolutionary Approach To Prostate Cancer](#) by cancer survivor Aubrey Pilgrim

QUICK REFERENCE

Full description of TNM [Staging](#) designations

A discussion of Clinical Stage with color illustrations is to be found in the [July, 2000 issue of INSIGHTS](#), published by the Prostate Cancer Research Institute (PCRI) with the financial support of the Life Extension Foundation. Call to be placed on the mailing list at (310) 743-2116, or Fax your request to (310) 743-2113. Or look for Newsletter at the [PCRI home page](#).

[Information on Markers and Tests](#) for prostate cancer.

[The Partin Tables](#)

[Expert pathologists](#) to confirm Gleason score.

[Questions](#) to ask your doctor.

HIGH DOSE RATE TEMPORARY BRACHYTHERAPY (HDR)

Listed below are some of the links and web sites relating to HDR. This is not intended to be a complete listing of all manufacturers, hospitals and centers involved with HDR, nor is it to be construed as an endorsement of any product or treatment center. These resources are listed to provide an overview of HDR and how it is performed.

These [Cancer Treatment Centers of America](#) at Tulsa (CTCA) Web sites have explanations of [HDR](#) while the web site of the [California Endocurietherapy Cancer Center](#) in Oakland, California also gives good information and [Brachytherapy/Seed Implants](#) provides some thought provoking material.

DIET & LIFESTYLE

The Prostate Cancer Protection Plan - The Food, Supplements, and Drugs that Could Save Your Life by Dr. Bob Arnot. This is a new book that includes nutritional and lifestyle recommendations for use in preventing and controlling prostate cancer.

[Choices in Healing](#): Integrating the Best of Conventional and Complementary Approaches to Cancer by Michael Lerner. Available on line.

Eating Your Way to Better Health: The Prostate Forum Nutrition Guide, by Charles E. Myers, Jr., M.D., Sara Sgarlat Steck, RT, and Rose Sgarlat Myers, PT, PhD.

Dietary advice is available through the [Prostate Cancer Foundation](#).

GENERAL INFORMATION

The [American Cancer Society](#) phone number is 1-800-227-2345. The American Cancer Society has a free program called "Man to Man" where survivors offer support to the newly diagnosed. There is also an interactive section in which people can e-mail oncology nurses with questions and obtain referrals.

[Prostate Cancer Research Institute](#) (PCRI) is a non-profit educational and research organization with valuable information regarding prostate cancer. PCRI publishes Insights, a newsletter

covering in-depth areas of key science and key concepts in prostate cancer. PCRI is at: Helpline number is 800-641-PCRI or 310-743-2110 EMail address is help@pcri.org

TREATMENT DECISIONS

A helpful guide to determining appropriate treatment options (a Decision Tree) is at the [National Comprehensive Cancer Network](#) site

Also consult: [National Cancer Institute](#) at 1-800-4-CANCER.

RADICAL RETROPUBIC PROSTATECTOMY SURGERY

The Prostate: A Guide for Men and the Women Who Love Them, by Patrick C. Walsh, M.D. and Janet Farrar Worthington.

PERSONAL ACCOUNTS

Surgery:

Man to Man: Surviving Prostate Cancer by Michael Korda. This is a book specifically dealing with a patient's experience with surgery. People report that it frightened them, but they were glad they read it. Your library may also have this book on cassette tape.

Prostate Cancer, A Survivor's Guide by Don Kaltenbach

My Prostate and Me by William Martin

Brachytherapy:

[Seeds of Hope](#) by Michael Dorso, M.D. may be available on line, but is now available as a paperback. This is a personal account by a doctor who had permanent seed implants (brachytherapy), hormone therapy and conformal beam radiation. Cost was \$6 to obtain it on line.

DISCUSSION GROUPS

If you have e-mail access, there are a number of discussion groups available to you for support and technical information, sharing experiences and asking and answering questions. All are free of charge.

Prostatepointers offers mailing lists specific to various treatment modalities and a support list

called "Circle." Address an e-mail to: Majordomo@www.prostatepointers.org leaving the subject line blank, and write "subscribe" in the body of the message. In a few minutes, you will be sent information on which discussion lists are on the system and how to subscribe to them.

An extensive network of discussion groups, archives, encyclopedia of information, practitioner lists for various therapies, lab recommendations for second opinions, Partin Tables, you name it, its there, at [Patients Helping Patients](#).

SUPPORT GROUPS

You may or may not wish to join a formal support group and attend their meetings. If you have the need or the curiosity, or just want to go to see what help you can be to others, your local hospital can probably put you in touch with your local chapter of [US TOO! International, Inc.](#)

A support group affiliated with the American Cancer Society is "Man to Man." Contact your local hospital or the National Cancer Information Center at 1-800-ACS-2345 to get information about your local chapter.

SHARING AND CARING

A website dedicated to helping men and their companions with the deeply personal issues created by prostate cancer is [Phoenix5](#). This site also features an [excellent interactive glossary of terms](#).

Another excellent and highly recommended support and information network is called "You Are Not Alone" ([YANA](#)) with a wealth of good advice and information

HELPLINES

Physician to Patient (p2p) is a mailing list which allows patients to ask specific questions related to their case of doctors who volunteer their time to write answers which are posted to the for the education of all. It can be accessed through: Majordomo@www.prostatepointers.org Address an e-mail as shown above, leaving the subject line blank, or show a dash (-) if required, and write "subscribe p2p" in the body of the message, and under it, write "end." In a few minutes, you will receive a welcome memo and

instructions on how to present your prostate cancer digest.

Prostate Cancer Research Institute (PCRI) has a telephone Helpline at (310) 743-2110.

PRACTITIONERS

The [Prostate Cancer Address Book](#) (PCAB) lists outstanding people in the world of prostate cancer.

SO...

You will change as a result of having prostate cancer touch your life. It's not ALL bad. You are a member of the fraternity now. And you have opportunities born of adversity to change the lives of others.

Many people report oddly incongruent benefits of having been diagnosed with cancer as they progress down this road. Some say that life seems more precious, their relationships improve, they find new joy in simple pleasures, they become more spiritual, they live each day as if it were their last, they appreciate everything more, they have found a new intimacy with their partners, they define sexuality in a more mature fashion, they have found new friends, formed new attitudes, embarked on healthier lifestyles...the list goes on and on.

We hope the information contained in this prostate cancer primer will be helpful to you and that you will discover additional information through your further research. Your first task is to educate yourself about your own condition, then hopefully, you will be in a position to educate other men and their families about prostate cancer and to urge them to have regular annual screening in the form of PSA testing and digital rectal exams.

We wish you low PSA's, and may your days be good, and long upon the earth.

Compiled and written by: Donna Pogliano
Partner of a warrior in the battle against prostate cancer. E-mail address: dpogliano@core.com

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