

PROSTATE CANCER

A BRIEF OVERVIEW

FROM THE HYPertext GUIDE TO PROSTATE CANCER

Revised and expanded June 2009

This overview is the work of a prostate cancer survivor who was treated in 1997. It will give you a basic understanding of what prostate cancer is and what you can do about it. You can learn more at www.hypertext.org by following the links to detailed information.

FINDING THE CANCER

The prostate is a gland about the size of a golf ball that is located directly beneath the bladder. It is part of the male reproductive system.

DETECTION

Prostate cancer does not produce any obvious symptoms in its early stages, which is one reason why regular physical exams are important. It is usually detected with two tests and confirmed with a third.

Digital rectal exam (DRE) Your doctor presses a gloved finger against the wall of the rectum next to the prostate. A slight hardness may indicate that there is a tumor.

Prostate-specific antigen (PSA) PSA does not cause cancer. The prostate produces it for other reasons, and some of it leaks into the bloodstream. If tumors develop, more PSA escapes.

If there are more than 2.5 ng/ml (nanograms per milliliter) of PSA in the blood, there may be BPH or cancer tumors in the prostate. A higher level of PSA may not be significant if a man is older or has a very large prostate—but a lower PSA does not necessarily mean that there is no cancer.

Biopsy A dozen or more very thin hollow needles are injected in specific areas of the prostate to collect cells. The biopsy should be guided by ultrasound and performed after the application of a local anesthetic. The absence of cancerous cells does not necessarily mean that there are no tumors. If there is persistent evidence of cancer (such as a rising PSA), a saturation or 3D biopsy may be necessary.

ASSESSING

Before you can choose a procedure, you must know the grade and the stage of the cancer.

GLEASON GRADE AND SCORE

The **Gleason grade** is a measure of the aggressiveness of the cancerous cells in the biopsy samples. It is estimated by a pathologist who assigns them values from one to five.

The **Gleason score** is the sum of the two most common numbers, for example, 3 + 4 = 7. The more common number is listed first. If that number is higher than the second one, the cancer is slightly more aggressive.

A score of less than six means the cancer is probably growing slowly, while seven and above suggests more rapid growth. But because most pathologists deal with many kinds of cells, the score may not be accurate. Get a second opinion of your biopsy slides from an expert pathologist who specializes in prostate cancer.

STAGES

The **clinical stage** is an estimation of the volume of the tumors and how far the disease has spread. It is determined from the results of the DRE, PSA, the number of biopsy samples (*cores*) that contain cancerous cells, Gleason score, ultrasound, and other information. (The *pathological stage* is more precise, but it can only be known by examining a prostate that has been surgically removed.)

Prostate cancer stages are usually classified as **TNM** (Tumor, Node, Metastasis) or **ABCD**.

Stages T1-T2c (or **A1-B2**) are called **local** cancers because the tumor is still inside the prostate.

Stages T3-T4b (or **C1-C2**) are called **extracapsular** or **regional** because the tumor appears to extend beyond the edge of the prostate capsule.

Stages N1-M1c (or **D1-D2**) are called **metastatic** or **systemic**. The cancer has reached the lymph nodes (N1-N3 or D1) or other parts of the body (M1-M1c or D2).

OTHER TESTS

Other tests may be needed to make the staging more precise and to establish the information (the *baseline*) against which the progress of your treatment can be measured.

STATISTICAL TABLES (nomograms)

Which procedures are appropriate for you will depend on your stage, score, age, and other factors. There are tables that may be able to help you decide. They were created by comparing the clinical stages of thousands of men with their long-term results.

The overall five-year-relative-survival rate for men with local cancers is almost 100%. And many men live much longer.

PREPARING

Don't waste time and don't rush into anything. It is more important to make an informed decision than a quick one.

HOW TO IMPROVE YOUR CHANCES

Keep calm No, it isn't easy, but stress will make your life harder and be harmful to your immune system. Anti-depressants, meditation, or other remedies may help. And do things that make you laugh. But set aside some time each day to continue learning about prostate cancer.

Join a support group It helps to know that you are not the only one with this problem, and to meet men who have dealt with it successfully. Speakers and group members may also provide useful information about treatments and doctors. But if someone strongly recommends the procedure he chose, he may be more anxious to convince himself than he is to convince you.

Talk to your family and friends Your cancer worries them too. Talking about it will help them deal with it and may also help you work out your own feelings. Give them copies of this overview to help them understand what is happening.

Change your habits Regular exercise and healthful eating habits can slow cancer growth.

Weight: Cancers need calories in order to grow, so avoid fats and alcohol, and don't overeat. Excess weight may also make it more difficult to treat the prostate and may contribute to the tumors' aggressiveness and the likelihood of recurrence.

Foods: Eat less meat, especially red meat, and more fruits, grains, legumes, nuts, berries, vegetables (especially green leafy ones), and fish. The minerals selenium and zinc may also help. Antioxidants, which have been shown to slow cancers, are found in vitamins C, D, and E. It's better to get antioxidants from foods such as onions, garlic, turmeric, and green, red, or white tea instead of pills—but don't take extra antioxidants during chemotherapy or radiation treatments. Drink at least two quarts of water a day but no more than two glasses of milk (limit calcium). And take a fiber supplement so you get at least 30 grams a day.

Look into neoadjuvant hormonal therapy (NHT) Prostate cancer needs testosterone in order to grow. Several months of neoadjuvant ("added before") hormonal therapy before a procedure can block testosterone production and shrink the tumors and prostate. Radiologists favor it because a smaller target means less damage is likely to be done to nearby organs,

THE MORE YOU KNOW, THE BETTER YOUR CHANCES

but surgeons are much less likely to recommend it. However, hormonal therapy or radiation is usually given *after* surgery in case any cancer cells escaped (*adjuvant therapy*).

Knowing that the cancer is getting smaller can reduce anxiety, but some of the potential side effects can be dangerous. Consult a specialist before you make a decision.

DO YOUR HOMEWORK

Not every case of prostate cancer requires treatment (see the section called *Waiting* on the next page).

If you do need to be treated, it is essential that you find out as much as you can about the entire process. You have to know what is happening—or *should* be happening—at every step. According to the *National Healthcare Disparities Report* in 2005, patients in the United States do not receive proper medical care 45% of the time—regardless of income, race, or other factors. The more you know, the better your chances.

Study your options carefully, and don't let anyone pressure you into making a decision before you've learned enough.

Books Read several, and choose carefully. Some are biased, incomplete, inaccurate, or outdated, and a famous name on the cover does not guarantee that a book will be helpful. Be wary of Web-page reviews with links to an online bookstore (they get paid for each sale). At this time the Hypertext Guide only recommends the books of doctors Dattoli and Strum.

Web sites There are a few very useful prostate cancer sites—and millions that are not. **Google Coop** lists sites selected by medical experts. (www.google.com/Top/Health/Conditions_and_Diseases/Cancer/Genitourinary/Prostate/)

On-line medical diaries Who better than a patient to tell you what each procedure actually feels like—and what to watch out for? There are many on the Web. Read all you need to, and weigh all of the positives and negatives.

On-line support groups These also offer opportunities to learn from others. **mailing lists** let you send questions and receive answers by e-mail. **Newsgroups** are on Web sites where you can leave and read questions and answers. Lists or groups with moderators are less likely to have arguments, spam, or misinformation.

Medical studies You can find them with specialized search engines like PubMed—but expect to find conflicting studies on every topic. (www.ncbi.nlm.nih.gov/sites/entrez)

News There are many on-line prostate cancer news sites as well as e-mail and postal newsletters, but not much useful news. Real progress does not occur every week.

INSURANCE (This section applies mainly to U.S. citizens.)

As if it weren't enough that you have to deal with cancer, you also have to navigate the business side of medicine.

If you are insured Read the fine print and keep careful records. Insurance companies and managed-care plans have a history of denying service. They are also known for expensive hidden charges, high deductibles, and canceling policies. A Harvard Medical School study found that 62% of all American bankruptcies in 2007 were caused by medical expenses. Three-quarters of those people had health insurance.

They may also try to wear you down with stall tactics or cut corners on your treatment. Once you decide what you want to do, make sure that the company has agreed to everything and that there have been no changes or substitutions.

If you are not insured Because you now have a *pre-existing condition*, no insurance company will sell you a policy, so be wary of offers. (Your state may have a high-risk insurance pool program, but most are very expensive and hard to join.) If you don't qualify for Medicare, Medicaid, or VA benefits, you may be able to work out payment programs with health-care providers and get help from a non-profit organization. (www.cancer.gov/cancertopics/factsheet/support/financial-assistance). Or you might try what some of the insured do when

they are denied treatment: travel to a country where good healthcare is more affordable (*medical tourism*).

DECIDING ON A PROCEDURE

You should consult with more than one kind of specialist in order to decide on a procedure. And once you have decided, you may still wish to find a different person to treat you. Why? Because some specialists have very little experience, some have not kept up-to-date, and some may not seem to care. If a doctor doesn't listen carefully to you, seems to be in a hurry, or just wants you to do as you are told, it's time to find another. Some specialists will only take on low-risk patients in order to maintain a high success rate. Being turned down does not necessarily mean that procedure is wrong for you.

Appointments Be on time and be prepared. Doctors don't have much time, so don't waste it. Learn as much as you can before an appointment, and bring a list of your questions. Bring a recorder in case you can't write down everything you are told. Have your spouse or a friend come along to help you focus. And it's a good idea to bring copies of your biopsy, clinical stage, and other key information to every appointment.

Questions

- Which procedures can I consider?
- What side effects are likely to result from each of them?
- Which procedure do I think makes the most sense for me?
- Who is the best specialist for that procedure?

Ask each specialist:

- Will my age or health make this procedure more risky?
- What other tests should I have?
- Are you board-certified for this procedure?
- How many of these procedures have you done?
- What is your personal success rate for survival without recurrence?
- How likely is it that the cancer could return?
- What can be done if it does return?
- What is your success rate for incontinence? Impotence?
- How soon would my life be back to normal?

TREATING EARLY-STAGE CANCER

The following descriptions are very general. You will need to do a lot more research in order to choose the best procedure for your particular circumstances.

Survival rates are about the same for all major procedures, but rates of incontinence, impotence, and other side effects vary widely. But be aware that *any* procedure may produce painful side effects, dangerous complications, or a recurrence of the cancer—even if you no longer have a prostate.

Mapping the prostate Ultrasound and CAT scan images are converted into 3D computer graphics to help determine the location of the prostate and tumors, and plan the procedure.

1. EXTERNAL RADIATION (RT, external-beam radiation, EBRT)
Concept Radiation damages cell DNA. Normal cells usually recover, cancerous cells do not.

Practice Patients go to a center five times a week for two months. During each session, radiation is aimed at the tumor.

Three-dimensional conformal radiotherapy (3D-CRT) directs the radiation from many angles so that it is more evenly distributed and less likely to damage other tissues and organs. It includes these forms:

Intensity-modulated radiotherapy (IMRT) An array of many microbeams of variable intensities can be adjusted to match the shape of the prostate from every angle.

Image-guided IMRT (IGRT, IG-IMRT, 4D) Small movements (such as breathing) can be tracked while the radiation is being given. The beams instantly adjust to changes in the shape or position of the prostate.

Proton-beam radiation (PBRT) The beams can be focused so that the energy reaches its strongest point inside tumors.

Advantages External radiation is usually painless. It can kill cancer cells at the edge of the organ. Everyday life is interrupted only by the daily sessions.

Disadvantages Nerves and nearby organs may be damaged and/or tumors may be missed. Skin over the target area may become red and sensitive. Patients may experience fatigue. Proton treatments are very expensive.

2. INTERNAL RADIATION (brachytherapy)

PERMANENT IMPLANTS (seeds)

Concept If the source of the radiation is *inside* the prostate, it can be more powerful, better focused, and constant.

Practice Tiny metal cylinders containing radioactive material are inserted in the prostate. The radiation diminishes over three to six months, depending on the material used.

Advantages Everyday life can be resumed right away. Some seeds may be placed outside the prostate to kill cancer cells that may have already escaped.

Disadvantages Nerves and nearby organs may be damaged and/or tumors may be missed. Temporary incontinence is likely to occur as the prostate and nearby organs react to the radiation.

TEMPORARY IMPLANTS (high-dose radiation, HDR)

Concept Tumors have little chance of recovering if they are hit with very high doses of radiation at the start of the treatment.

Practice Highly radioactive materials are inserted through temporary tubes for brief periods over several days. This is followed by a regular course of external-beam radiation.

Advantages Tumors receive much higher doses of radiation than would otherwise be possible. Everyday life is interrupted only by the initial hospital stay and the daily sessions.

Disadvantages Patients remain in a hospital bed during the high-dose stage. Nerves and nearby organs may be damaged and/or tumors may be missed. Patients experience fatigue.

3. SURGERY (radical prostatectomy, RP)

Concept If the prostate comes out, so does the cancer.

Practice There are three kinds of prostatectomy. The **retropubic** is done by opening the lower abdomen, the **perineal** is done by entering behind the testicles, and the **laparoscopic** by inserting special instruments and a tiny video camera through small incisions in the abdomen.

Advantages Patients feel relieved because the prostate is no longer there. If it appears that the cancer has escaped (there are *positive margins*), measures can be taken to stop it.

Disadvantages It requires cutting open the body (is *invasive*). Nerves and nearby organs may be damaged and/or part of the cancer may escape or be left behind. Recovery may be slow and painful. A catheter must be worn for a week or more.

4. FREEZING (cryotherapy, cryoablation, cryosurgery, cryo)

Concept Freezing kills cells.

Practice A cooling solution is sent through the prostate using thin needles. Some techniques can target only the tumors.

Advantages It is fast, relatively painless, not invasive, and comparatively inexpensive. Everyday life can soon be resumed.

Disadvantages Normal cells cannot recover from freezing. Nerves and nearby organs may be damaged and/or part of the cancer may be missed. Dead tissue may block the urethra. A catheter must be worn for about a week.

5. HEATING (high-intensity focused ultrasound, HIFU, FUS)

This technique has not yet been approved for use in the United States, but it is available in many other countries.

Concept Extreme heat kills cells.

Practice High-energy ultrasonic waves are focused on tumors. Only the tumors and nearby normal cells are killed.

Advantages It is fast, relatively painless, not invasive, and comparatively inexpensive. Everyday life can soon be resumed.

Disadvantages Normal cells cannot recover from extreme heat. Nerves and nearby organs may be damaged and/or part

of the cancer may be missed. Dead tissue may block the urethra. A catheter must be worn for about a week.

6. WAITING (watchful waiting, active surveillance, expectant therapy)

Concept If the tumors are small and appear to be growing very slowly, the Gleason score is very low, and life expectancy is less than fifteen years, the potential side effects make any procedure more likely to harm than to help.

Practice Regular DREs, PSA tests, and biopsies.

Advantages The tumors' growth may be slowed by adopting more-healthy habits and neoadjuvant hormonal therapy. There is still time to perform a procedure.

Disadvantages There may be unidentified tumors, the cancer may begin to grow more rapidly, or the patient may live much longer than expected. And it's not easy to keep from worrying.

SIDE EFFECTS

How you feel afterward will depend on your general health, age, the type of procedure, your doctor's skill . . . and a certain amount of luck.

Before any procedure, ask your doctor about probable pain and other side effects, and what remedies will be available. This applies to both early- and late-stage patients.

Incontinence Some type of urinary problem usually occurs soon after any procedure and may continue for days or months. Incontinence is permanent in some cases, but there are ways to reduce or manage the problems it creates.

Impotence Most men will be impotent for a short while after any procedure. For some, erectile dysfunction is permanent, but in many cases it can be treated with drugs or other methods.

GETTING YOUR LIFE BACK

It's not quite over when the procedure is. You must return a few times over the following months to be checked for any problems that might arise. If you are treated far from home, stay in that area for a few days in case any complications arise. Always tell your doctor everything. Don't hold back things that embarrass you.

If the cancer did not escape, you have a good chance of leading a reasonably normal life. You should continue to eat well, exercise, and have regular PSA tests and checkups for other symptoms to make sure the cancer has not returned.

Recurrence The longer you are cancer-free, the less likely it is that the cancer will return. A recurrence is usually detected by a rapid rise in PSA (*biochemical failure*). But PSA levels can vary from test to test, especially in the months after a procedure, and a rise may not mean anything. Even if the cancer does return, there are procedures (*salvage therapies*) that may be able to get rid of it. Worrying about recurrence (*PSA anxiety*) makes it difficult to enjoy the good things in your life.

TREATING ADVANCED CANCER

Once cancer spreads to other parts of the body (*metastasizes*), there is no treatment that can stop it. There are only therapies that can reduce pain and extend life. The treatment of pain (*palliation*) should begin as soon as the pain does.

HORMONAL THERAPY (androgen blockade, hormone blockade)

This is usually the first line of treatment.

Concept Reducing testosterone production slows tumor growth.

Practice Shots, pills, or castration.

Disadvantages Side effects usually include hot flashes, the loss of sexual desire, and some more-dangerous ones. And in time the tumors will be able to grow without testosterone.

Advantages When the cancer no longer needs testosterone, stopping the blockade will slow growth once again.

RADIOTHERAPY

This is mainly used to relieve pain.

Concept Radiation can reduce the size of tumors that press against nerves and bones.

Practice Patients are given external radiation or injections of radioisotopes that migrate to the tumors.

Disadvantages Fatigue, lowered immunity, skin reactions, and other side effects may occur.

Advantages Patients feel better and may live longer. Bones are less likely to fracture.

CHEMOTHERAPY (chemo)

This is not begun until hormonal therapy fails.

Concept Certain toxic drugs can slow the spread of cancer and relieve symptoms caused by tumor growth.

Practice Drugs are introduced into the bloodstream during a series of hospital visits.

Disadvantages Strong side effects, possible nerve and kidney damage, and reduced immunity. It is not effective for long.

Advantages Patients live a little longer.

DEFINITIONS

Cancer Glossary www.cancer.gov/dictionary/

Prostate Glossary www.prostate-cancer.org/resource/pdf/

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Complementary therapies supplement medical treatments (for example, using biofeedback to help regain control of pelvic-floor muscles). Check with your doctor before trying any complementary therapy, even a change of vitamins.

Alternative therapies are not supported by any scientific evidence—for example, the claim that shark cartilage is a cure for cancer. Alternative therapies may raise unrealistic hopes, interfere with your treatment, or be intended to cheat you.

COUNSELING

Cancer takes an emotional toll as well as a physical one, and men and their families can benefit from counseling. This is especially true for men who have problems with side effects. (There are some support groups for specific side effects.)

OTHER THINGS YOU CAN DO

Talk about prostate cancer Millions have survived prostate cancer, but few people are aware of it. That's because most men are too embarrassed to talk about it, even with their closest friends. But what you tell them might save their lives.

Donate some of your time Newcomers to support groups can benefit from talking to men who have been treated, so stick with a group for a few years after you have been treated. Your information may be helpful—especially if your procedure did not go perfectly. If you are good at organizing, help with fundraisers or public awareness events; if not, there will still plenty of other work to do.

Contribute to research Give money and ask your friends to do the same. Survival rates are rising thanks to advances in research and procedures. If you have advanced cancer, enroll in a clinical trial. It will offer only a tiny chance of survival, but it may help save men of your children's generation.

Write your representatives There are more cases of prostate cancer in the U.S. every year than of breast cancer, yet the government spends more money on breast cancer research.

In large part, that is because women are willing to speak out. And they keep after Congress. Remind the men in Washington and your state legislature that many of them are going to develop prostate cancer some day, and that it is in their own best interest to promote research *now*. Letters and phone calls carry more weight than e-mails. Voting carries much more.

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Endorsements A study of cancer information on the Internet stated that the "high quality and informative sites investigated by the authors include the Hypertext Guide to Prostate Cancer." More endorsements can be found at:

www.hypertext.org/ENGLISH/recommendations.html

Disclaimer This overview is only intended for educational purposes. It is not a substitute for informed medical advice from a physician.

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YOU'LL NEED MORE INFORMATION TO BE ABLE TO MAKE AN INFORMED DECISION

YOU CAN FIND IT AT www.hypertext.org/ENGLISH/OVER.html

The *Hypertext Guide to Prostate Cancer* Web site is still incomplete. It takes an enormous amount of time to find accurate, useful information and to explain it clearly. For example, the latest expansion of this overview took more than 60 hours of researching, writing, reviewing, proofreading, and coding. But the 20-plus other pages on the site will require much more time, and there are more topics to come.

Donations would enable me to hire people to do much of the necessary research.

How much is this information worth? If you've already tried to digest an entire book on prostate cancer, you know how valuable this overview alone is. It would help a lot if you gave even a fraction of what that book cost.

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