



Making the Choice

Deciding What to Do About **Early Stage** Prostate Cancer

"We have all faced the same tough choices you face now.
We talked with our doctors and others we love and trust.
We each made our choices. You can too.
This booklet will help you make your choice."



Contents: What's in This Booklet

Getting Started	Page
• How Prostate Cancer is Different	2-3
• Understanding Your Prostate	4-5
• What Your Test Results Mean	6-7
• Planning Your Treatment: How to Use Your Test Results	8-9
Treatment Choices	
• A Treatment Choice: Watchful Waiting	10-11
• A Treatment Choice: Surgery	12-13
• A Treatment Choice: Radiation	14-15
• Comparing Treatment Choices	16
• Comparing Side Effects.....	17
Beyond Treatment	
• After Your Treatment is Finished	18-19
• Things to Ask Your Doctor/Things to Think About	21
Words to Know and a Place to Write	
• Medical Words Used in the Booklet (Glossary)	22-23
• A Place for You to Take Notes	24
• A Place to Chart Your Progress	25
• Education and Support Groups	25

This booklet is designed to help you understand medical facts and to talk with your doctor. It is not medical advice. It should not take the place of your doctor's advice and suggestions. Talk with your doctor about all your treatment choices.

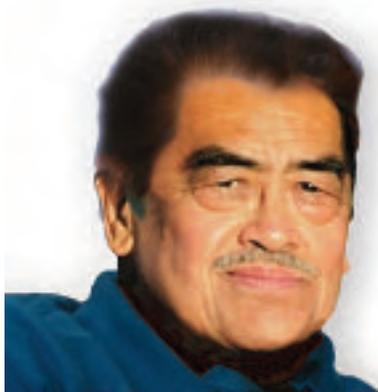
Hearing the Words “You Have Prostate Cancer”: What Some Men Have Said



“When I first learned I had prostate cancer, my wife and family were all upset. They tried to give me advice and started to treat me like a sick person. Lucky for me, my minister had been through this. He calmed the family down. Then we could all talk together about the best thing to do.”



“When my doctor told me I had prostate cancer, I couldn’t believe it. After he said the word cancer, I didn’t hear anything else. I had to get over the shock before I could learn more and start thinking about what I wanted to do.”



“When my doctor told me I should help make the decision about how to treat my prostate cancer, I was surprised. I thought doctors were supposed to make those decisions. — But, after my mind cleared, I learned all I could about the different treatments. Together, my doctor and I chose what seemed best for me. This brought me peace of mind.”

Using this booklet to help

If a biopsy has shown that you have early stage prostate cancer, this booklet is for you. It gives you the facts about your disease, your treatment choices, and the possible results of those choices.

Even if you choose to let the doctor decide, you need to be well informed.

Learn all you can so you can make your choice. Share this booklet with your doctor and loved ones. Talk to people you trust. Many others have learned and coped. You can too.

Prostate cancer is different from other cancers. Get the facts before you decide what to do.

It's not easy to understand prostate cancer.

- On the one hand, it *is* cancer. So, like other cancers, there's a chance it could grow and spread and even cause death.
- On the other hand, prostate cancer is a very *different* kind of cancer. Most prostate cancers grow very slowly and never cause problems. A few grow quickly.
- In the early stages, doctors can't always tell how *your* prostate cancer will act.
- If men live long enough, most will have cancer cells in their prostate, but few will die of it. About 60 out of 100 men over the age of 70 have cancer cells whether they know it or not.

Here's the bad news and the good news about prostate cancer.

- It's the most commonly diagnosed cancer of men, not counting skin cancer.
- BUT only 3 out of 100 American men will die from it. Most men die WITH prostate cancer, not FROM prostate cancer because it is slow growing.

It's not easy to choose the best treatment.

Even the doctors don't always agree.

There are 3 standard treatments for early prostate cancer: Watchful waiting, surgery, and radiation.

Watchful waiting is just what the name says. Your doctor keeps a close watch on you at regular checkups. But, nothing is done to get rid of the cancer unless it starts to grow or cause problems. You can choose to begin active treatment at any time.

Surgery and **radiation** are *active* treatments. They may cure you, but they may also cause side effects, such as:

- Trouble controlling your bladder
- Trouble controlling your bowels
- Trouble having an erection.

The number of men alive at the end of 10 years, after watchful waiting, surgery or radiation, is about the same.

What does the best research say to do?

It is still not clear. Here's why:

You may have heard about an important Swedish study published in 2005. This study showed an improvement in survival and in limiting cancer progression and spread with surgery compared to watchful waiting. The benefit of surgery seemed to be greater for men less than 65 years old.

While the Swedish study supported surgical treatment, another study suggested that patients with **low grade cancer** (Gleason score less than 5) continued to have a low risk of dying from prostate cancer even after 20 years.

All information in this booklet comes from medical research.

References are available from The Michigan Cancer Consortium.

Call toll free: 877 - 588 - 6224 or visit on the Internet: www.michigancancer.org

The Decision is Up to *You*. Different Men Make Different Choices.

So, as you can see, there are a number of things to think about.

- You now have prostate cancer and need to decide on a treatment.
 - You do not have a cancer that you *know* will get worse.
 - Early stage prostate cancer is different. It *may* get worse. But it may *not*.
 - The treatment may save you. Or it may cause problems that you could have avoided.
 - Some doctors will advise you to treat it. Some will advise you to wait and see.
-

You have to balance 2 things about treatment.

- If you choose to treat it, you have a chance for a cure.
 - If you choose to treat it, you may have serious side effects from the treatment.
-

Get as much information and support as you need.

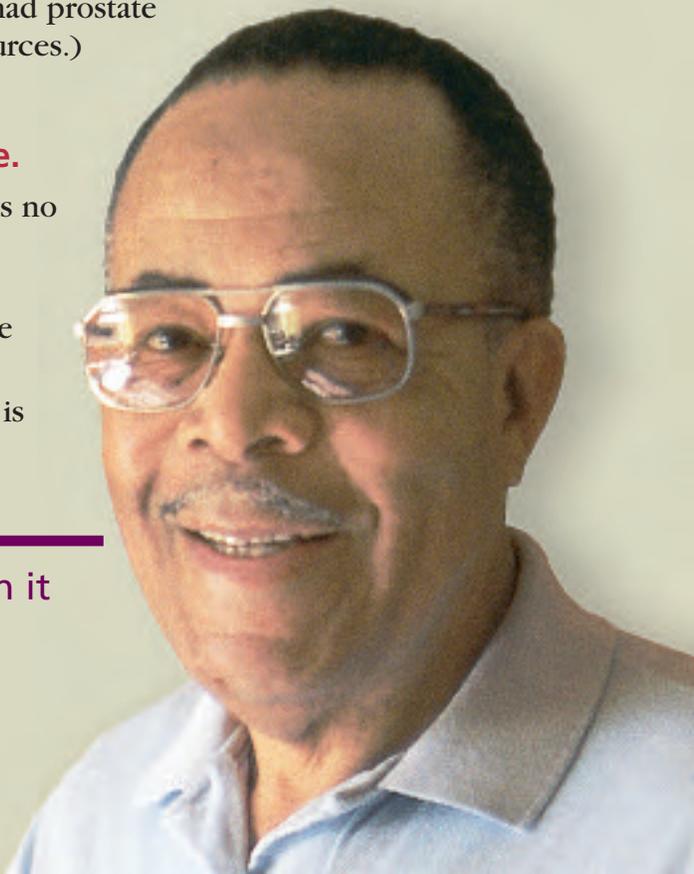
- Talk to your doctor and other health care providers.
 - Talk to your partner and family, and other people you trust.
 - Talk to other men who have had prostate cancer. (See page 25 for resources.)
-

Don't be pressured. Read.
Ask questions. Think. Then decide.

- Each man is different. There is no right or wrong decision.
 - You can get a second medical opinion. Ask if your insurance pays for it.
 - Try to make the decision that is best for *you* — one you can live with.
-

"I had to learn a lot and think on it before I could decide what treatment I wanted.

My doctor told me to take the time I needed."



Understanding Your Prostate: What It Is, Where It Is, What Can Happen

What it is and what it does

The prostate is one of the male sex glands. When a man has sex, some fluid from the prostate mixes with the sperm made in the testes. Then, the fluid (semen) gets squeezed out through the penis.

The prostate makes another substance important to you right now called PSA (**P**rostate **S**pecific **A**ntigen). Doctors measure the amount of PSA through a blood test to check for certain problems. PSA can be higher than normal in men with prostate cancer as well as with some other prostate conditions such as prostate enlargement (BPH) or prostatitis.

Where it is

Look at the picture on the next page. The prostate lies just inside your body, below the bladder and in front of the rectum. That is why the prostate can be felt through the wall of the rectum.

When it is healthy, it is about the size of a walnut. It surrounds the tube called the **urethra** (u-REE-thra) that carries urine and semen out of the penis.

What can happen to it

Normal Prostate: As you get older, the prostate can grow.

Enlarged Prostate (Benign Prostate Hyperplasia or BPH): If the prostate gets too large, it can make it hard for a man to pass urine (urinate). That's because a larger prostate gland can press on the tube that carries urine and semen out of the penis.

Prostatitis (prah-stah-TI-tiss): The prostate can become inflamed if irritated, or if you have an infection in the area of the bladder or prostate.

Prostate Cancer: The prostate can also develop cancer. If there is cancer, cancer cells can spread to the nearby tissue. Cancer cells can also get into the bloodstream and spread to other parts of the body. This includes lymph nodes and seminal vesicles. (See page 23 for definitions.)

See the drawings on page 5 to find these other parts of your body that can be affected by prostate cancer

Lymph Nodes: Small glands that filter germs and are next to the prostate.

Seminal Vesicles: Small sacs that store semen and are attached to the prostate.

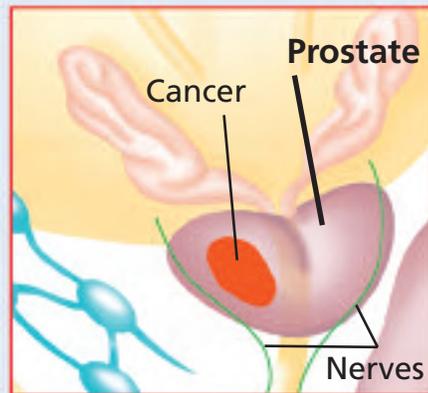
Nerves: Bundles of nerves running next to the prostate that allow a man to have an erection.

The prostate and the surrounding organs

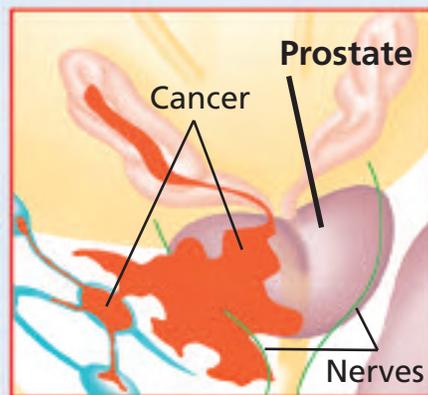
This drawing shows the position of the prostate and the organs that are in the same area. The view is from the back, looking through the body.

Detail drawings of a cancerous prostate and the area directly around it

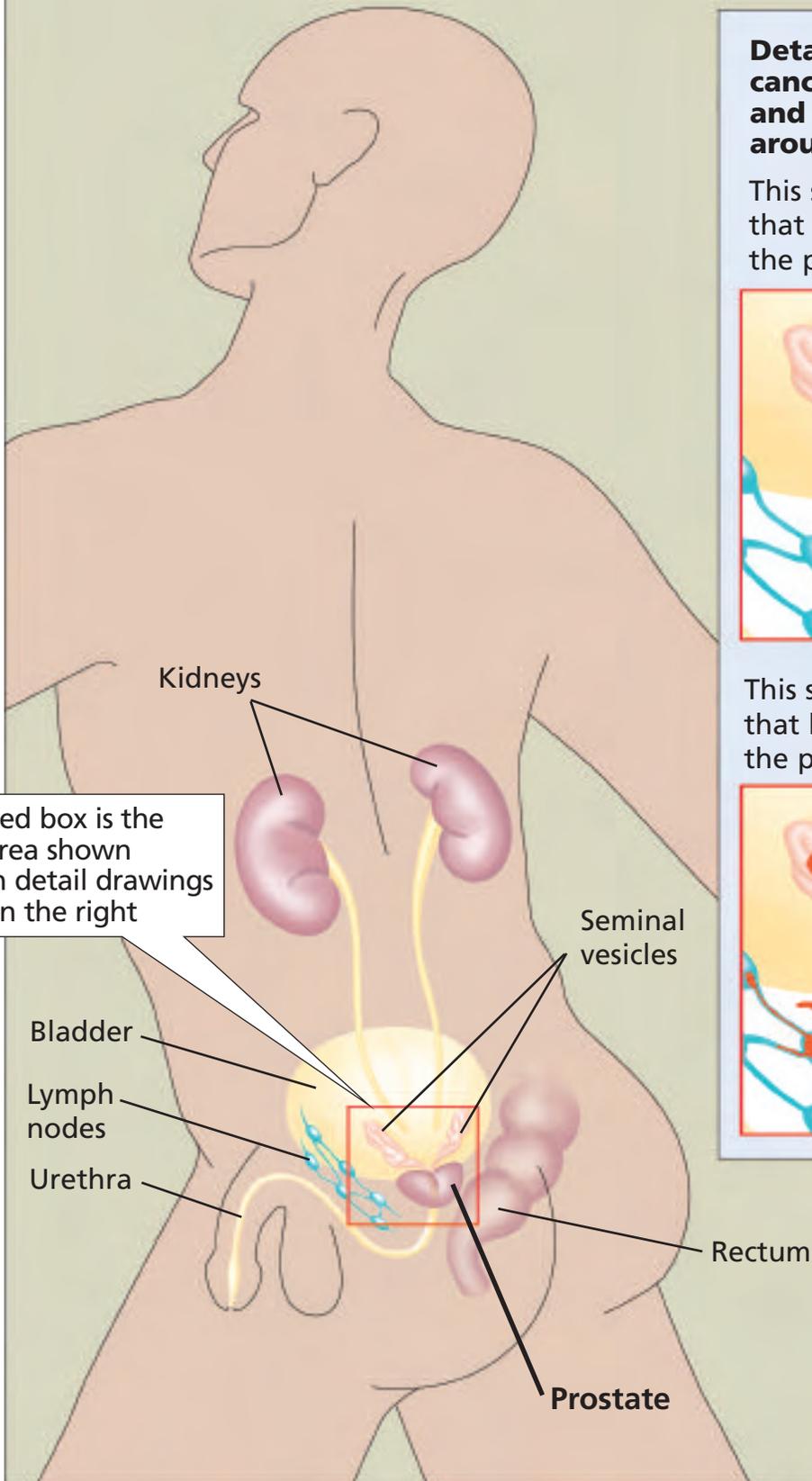
This shows cancer that is contained within the prostate.



This shows cancer that has spread beyond the prostate



Red box is the area shown in detail drawings on the right



What Your Test Results Mean

You have been told that you have prostate cancer. You have had a biopsy and possibly other tests that tell if your cancer may have spread. These tests give information, but are not perfect.

1. The PSA test

The PSA test tells you HOW BIG your tumor *probably* is and if it *may* be spreading.

- The PSA is usually higher in men with prostate cancer. What matters is HOW MUCH higher it is.
- The PSA numbers below only apply to men who have been diagnosed with prostate cancer.

Write your PSA number here.

- If your PSA was less than 10, the chances that treatment will work are **pretty good**. (This includes watchful waiting, surgery, and radiation.)
- If your PSA was between 10 and 20, there is some **cause to be concerned**.
- If your PSA was more than 20 the chances that treatment will work are **not so good**.

2. The GRADE of the cancer

The grade of the cancer tells you HOW FAST your tumor is *likely* to grow. The grade may be called the Gleason Sum or the Gleason Score.

- When you had a biopsy, doctors removed some cells from your prostate. Then, they used a microscope to see how fast the cancer cells seem to be growing.
- Based on what they found, they graded the tumor. Then they gave you a number called the **Gleason Sum**. It is a *best* guess of how fast your cancer might be growing. But it is not a *perfect* guess. The Gleason Sum ranges from 2 to 10.

Write your Gleason Sum here.

- If your Gleason Sum was 2, 3, 4, or 5, the cancer is **likely to grow slowly**.
- If your Gleason Sum was 6, or 7, the cancer is **likely to grow at a medium rate**.
- If your Gleason Sum was 8, 9, or 10, the cancer is **likely to grow fast**.

3. The STAGE of the cancer

The stage tells you HOW BIG your tumor is and HOW FAR it has spread.

- The treatment your doctor recommends depends partly on whether your tumor has spread out of your prostate. If the cancer has spread, the results of treatment will probably not be as good.
- To figure out your stage, your doctor may recommend getting a bone scan, CT scan, MRI or other tests to see if your cancer has spread.
- There are 2 systems of letting you know what stage the cancer is in.
 1. One system uses letters and numbers, for example, T1, N0, M1. (T is tumor size, N is lymph nodes involvement, and M tells that the cancer has spread or metastasized)
 2. The other system uses letters from A through D. See below.

Write your stage here.

And then, check which statement is true for you.

Is your cancer confined to the prostate?

- Yes No I'm still waiting for the results of other tests

What the Stage Means

The Stage	What Doctors Call It		What It Means
	A-D System	TNM System	
Early stage [Cancer only in the prostate itself — what this book is about]	Stage A	Stage T1	The tumor has <i>probably not spread</i> to other parts of the body.
	Stage B	Stage T2	The tumor is large enough for a doctor to feel. It has <i>probably not spread</i> to other parts of the body.
Later stage [Cancer outside the prostate]	Stage C	Stage T3/T4	The tumor has spread to tissue next to the prostate.
	Stage D	Stage N+/M+	The tumor has spread to other parts of the body as shown by bone or CT scans.

Planning Your Treatment: How to Use Your Test Results

The PSA, the Grade and the Stage

Taken together, PSA, Grade, and Stage will help your doctor figure out which treatments might be successful in controlling or curing your cancer.

Just to review, here's what these numbers mean.

1. The PSA

Although the test is not perfect, here are some guidelines.

- The lower the PSA, the better the chances are that treatment (watchful waiting, or surgery, or radiation) will be successful.
- The higher the PSA, the less likely that treatment will be successful.

2. The GRADE of the cancer (This is also called the Gleason Sum)

The grade gives a good guess about how fast the cancer seems to be growing.

- With a low grade, the tumor may be slow growing.
If so, it may be slow growing for years. It may never cause problems for you.
- With a high grade, you are in danger of having it spread beyond the prostate.
The higher the grade, the faster growing (or aggressive) the cancer.

3. The STAGE of the cancer

The cancer stage gives you a good guess about how much it may have spread.

- The lower the stage, the better the chance of a successful treatment.
- As the stage gets higher, chances of a successful treatment go down.



“We struggled together to learn what the PSA, the Gleason Sum, and the Stage meant about my cancer.

My wife came to doctor’s appointments with me. She was great support without telling me what to do.”

Other concerns you and your doctor may talk about

1. Your age — older or younger

- Watchful waiting may well be the treatment of choice for older men. This is even more so for older men with other medical problems. The older you are, the less likely prostate cancer will cause problems in your lifetime.
- But a man with more than 10 years to live may live long enough to develop problems with his prostate cancer.

2. Your general health — in good health or not

- Other health problems may shorten your life enough that prostate cancer may never bother you.

3. Your own values and feelings — the things that mean the most to you

- Some men want active treatment, even if they seem to have a slow growing tumor.
 - They want the cancer treated no matter what.
- Other men want to wait and watch. They are more concerned that active treatment may mean:
 - They may have trouble controlling their urine or their bowels.
 - They may have trouble having an erection.
- Only you know what will make you feel that you have made the best decision.

4. If you are African American

- African American men are often diagnosed at a younger age than white men and with more advanced prostate cancer. However, treatment may be equally successful for both groups if given the same care.

What other people may have to say

1. Your family and spouse

- You may want to talk this over with your wife or partner, or other people you trust.
- You may prefer to make your own decision.
- You may want to talk to other men who have had prostate cancer. (See page 25 for resources.)

2. What doctors recommend

- Your doctor will probably tell you which treatment she or he thinks is best suited for you.
- You might consider seeing another surgeon, radiation oncologist, or a medical oncologist to get more advice. This is called a second opinion.
- If you get a second opinion, your insurance may or may not pay for it.

A Treatment Choice: Watchful Waiting

What happens

- With watchful waiting you do not start active treatment yet.
- You and your doctor watch for signs that the cancer may be changing, growing or spreading.
 - You have regular doctor visits and examinations.
 - You keep getting tested. You will have tests like the ones you have already had.

“When the doctor told me that I could choose watchful waiting, I thought maybe he didn’t want to take care of me. But that’s not what he meant at all.

He meant he would keep a close watch on my cancer to make sure it wasn’t growing or spreading. It’s a wait and see approach. I had to decide if this was for me.”



How this treatment can help

- Some doctors think it's a good idea to do watchful waiting if the following applies to you:
 - You have a small cancer confined to the prostate gland. And it does not appear to be spreading or growing fast.
 - You are older or have a lot of serious health problems. And you may not live long enough for the cancer to cause any problems.
- You do not have to deal with side effects or complications of active treatment like:
 - trouble controlling your bladder or your bowels.
 - trouble having an erection.
- You can always change your mind and begin active treatment.
- It is low in cost (time and money).

How this treatment may cause problems

- The cancer could quietly spread and become harder to cure.
- If not carefully followed, the cancer may progress in the prostate area and cause you symptoms such as difficulty passing urine, bleeding, impotence, or pain.
- It can be stressful to go on with daily life not knowing what your cancer might do.
- A new study shows that after 15 years prostate cancer may spread more quickly than previously thought.

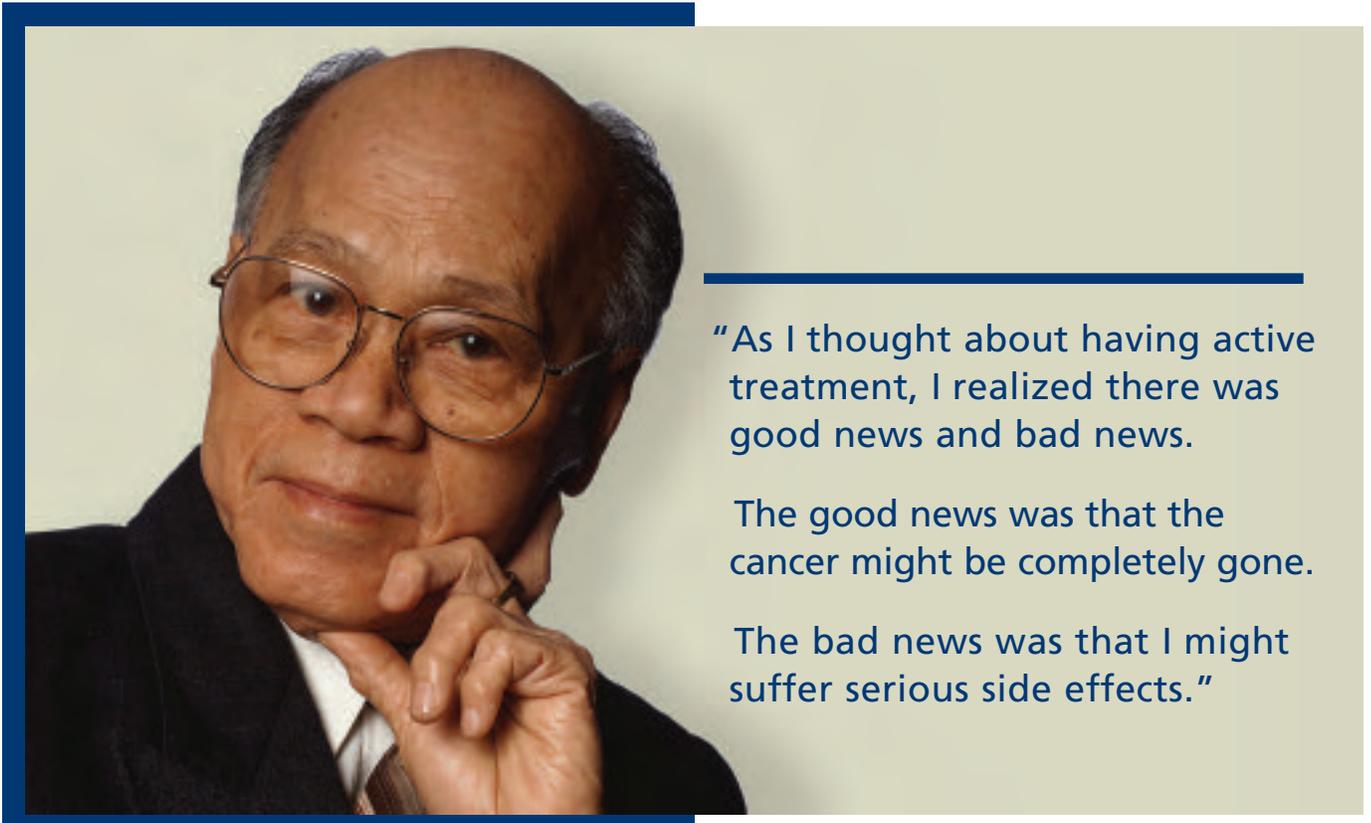
A Treatment Choice: Surgery (Also called **Radical Prostatectomy**)

What happens

- You will be admitted to the hospital for one or more days.
- During surgery, the surgeon will remove the entire prostate gland with the cancer in it. Sometimes, the doctor will also remove the lymph glands (nodes) next to the prostate.
- The surgeon can get to the prostate through the lower abdomen or from in between the legs, near the scrotum. Another way to remove the prostate is to put a lighted tube (called a laparoscope) through the abdomen into the body either by the doctor alone, or by using a robotic device (also known as robotic surgery).
- In some cases, the surgeon can do a “nerve-sparing” surgery. This can reduce the chance that a man will have problems holding his urine or having sex after surgery. But for some men, this cannot be done. If the cancer is too near the nerves, the surgeon might have to cut out the nerves so no cancer is left behind.
- A tube (catheter) will be placed in your bladder to drain your urine. It will be left in for a short time.

How this treatment can help

- If the tumor has not spread, and the surgeon gets all of the cancer out, a man can be free of prostate cancer for the rest of his life.



“As I thought about having active treatment, I realized there was good news and bad news.

The good news was that the cancer might be completely gone.

The bad news was that I might suffer serious side effects.”

How this treatment may cause problems

1. The surgeon may not get all of the cancer out.

2. You can have complications from the surgery.

- **Bleeding:** You can have bleeding that may require a blood transfusion.
- **Blood clots:** You can have blood clots in the legs or lungs.
- **Infection:** You can have an infection at the incision where surgery was performed.
- **Problems holding urine:** You may not be able to hold your urine. You may leak if you cough, sneeze, or strain yourself (like when you lift something), or change position all of a sudden.
 - Leaking may last from a few weeks to several months or longer. In this case, the leaking stops without the need for special treatment.
 - In about 9 men in 100, it doesn't get better. In this case you can use a clamp or have special surgery. This will usually control the leakage. For 91 men out of 100, this is not necessary because the problems with leakage get better.
 - Problems holding urine are less for younger men.
- **Problems passing urine:** You can have scars inside the tube (the urethra) that carries urine out of the penis. About 15 men out of 100 may have this problem.
 - This can make it hard to pass urine.
 - You can have a procedure to unblock the tube.
- **Problems having or keeping an erection (impotence):** You can have trouble having or keeping an erection. This may affect your feelings about sex and about yourself. But it is possible to have sexual pleasure even without an erection or an ejaculation (dry orgasm).
 - About 60 men out of 100 have permanent impotence following surgery. About 40 out of 100 men will have their original levels of sexual ability.

The risk of being impotent depends on a few things:

 - How good your erections were before surgery.
 - The surgical technique.
 - Your age.

Your doctor can help you treat the impotence with:

 - Medicine that helps with erections.
 - Vacuum device.
 - Injections into your penis.
 - Surgical implant.
- **Lastly, there is a risk of death with any surgery:** It can happen to about 2 men out of 1,000. This means that 998 men out of 1,000 live through surgery.

After surgery, most men will feel relieved, but some may also feel sadness. If your sad feelings are just too strong, ask your doctor to suggest help.

A Treatment Choice: Radiation

What happens

There are 2 types of radiation treatments: Your doctor may advise one over the other depending on your cancer.

1. External beam radiation

- This method fights the cancer with radiation from **outside** of the body.
- The medical team will direct a beam of radiation at your prostate.
- You do **not** check into a hospital. You get treated as an outpatient.
- You go to a hospital or a clinic 5 days a week, for 7 to 8 weeks.
- Each treatment lasts about 15 minutes.
- **Conformal** external beam radiation is a better way of directing the radiation to the prostate. This will lead to fewer side effects and better control of the cancer than regular beam radiation.

2. Internal seed radiation: Also called brachytherapy (bray-kee-THER-a-pee)

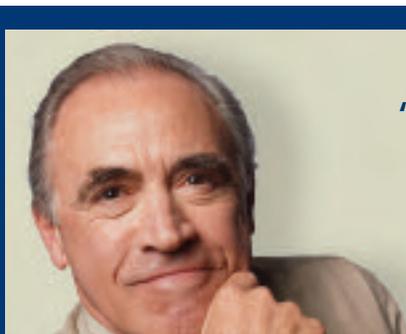
- Radiation seeds are placed into the prostate.
- You do **not** check into a hospital. You get treated as an outpatient.
- The seeds destroy cancer cells inside the tumor. But they do not do much damage to the tissue around the prostate.
- Doctors sometimes use external beam radiation along with seeds.

If you choose radiation treatment, your doctor may also suggest that you take medicine to reduce your male hormones.

- The combination has been shown to improve the chances that your treatment is successful.
- Hormone therapy may last for several months. It may mean getting regular injections. It can be stopped if it is not working.
- This can have its own side effects such as loss of sexual desire, hot flashes, and loss of energy.

How these treatments can help

- If the tumor has not spread, and the radiation kills all of the cancer cells, a man can be free of prostate cancer for the rest of his life.
- The problem with erections may be less likely than with surgery, but more likely than with watchful waiting.
- There may be fewer problems with holding urine than with surgery (less leaking).



“Learning all the new words to talk about possible radiation treatment was a challenge. The doctors were patient with me, and helped me really understand what the treatment would be like.”

How these treatments may cause problems.

1. Radiation may not kill all of the cancer cells.
2. You may have some side effects from either type of radiation, but how often they happen may be different.

- **Problems holding your urine:**

You may have just a few weeks of not being able to control your urine.

- But about 2 to 4 men out of 100 have this as a permanent problem for internal seed radiation. This means 96 to 98 men out of 100 will not have any urination problems.
- This is rarely a problem for men receiving external beam radiation.

- **Problems passing urine:**

It may be painful or difficult to pass urine. The pain when passing urine may be due to an inflamed prostate or urinary tract infection.

You may also have to pass urine more often.

- For about 92 out of 100 men this does not happen or is only temporary.
- It will be a permanent problem for about 8 men out of 100 receiving external beam radiation, and possibly more with internal seed radiation.

- **Loose bowel movements (diarrhea), pain, or bleeding from the rectum**

For more than 90 men out of 100 this is temporary or does not happen.

- For both types of radiation, this is permanent for about 8 men out of 100.

- **Problems having and keeping an erection (impotence):**

Just as with surgery, you may have trouble having and keeping erections.

This may affect your feelings about sex and about yourself. But it is possible to have sexual pleasure even without an erection or an ejaculation (dry orgasm).

- For both types of radiation, about 45 men out of 100 have permanent impotence. This means that 55 men out of 100 will have their original level of sexual ability.

Your doctor can help you treat the impotence with:

- Medicine that helps with erections.
- Vacuum device.
- Injections into your penis.
- Surgical implant.

After radiation, most men will feel relieved, but some may also feel sadness.

If your sad feelings are just too strong, ask your doctor to suggest help.

Other things to think about.

- With external beam radiation, you may feel weak and tired during the weeks treatment is being given. (See chart on page 16.)
- Internal seed radiation has not been used as long as external beam radiation. So the chances of cure and side effects are less well known. (See chart on page 16.)
- If radiation does not cure your cancer, surgery may be more difficult because of scarring around the prostate from radiation.

Treatment Choices for Early Stage Prostate Cancer

How to use this table

Read across to learn the advantages and disadvantages of each treatment.

Read down to compare treatments.

	Advantages	Disadvantages
Watchful Waiting	<ul style="list-style-type: none"> • It is low in cost (time and money). • No side effects or complications from the treatment itself. • May never need active treatment. 	<ul style="list-style-type: none"> • Prostate cancer may spread and become incurable. • Prostate cancer may get bigger and cause symptoms. • May lead to more cancer deaths than surgery for cancers found because of symptoms. • Involves living with uncertainty.
Surgery	<ul style="list-style-type: none"> • May remove all the prostate cancer. • Gives best idea on how big the cancer is. • May lead to fewer cancer deaths than watchful waiting in cancers found because of symptoms. • Avoids prostate inflammation. 	<ul style="list-style-type: none"> • The cancer may not be completely removed. • May have problems <i>during</i> surgery. • Requires you to be in a hospital. • May have problems having erections. • May have problems holding urine. • May have limited activity for several weeks. • Rarely, may die as a result of surgery.
External "beam" radiation	<ul style="list-style-type: none"> • May kill all the prostate cancer. • Usually not as hard on your body as surgery. • Do not need to be admitted to a hospital. • May have fewer problems with holding urine than surgery. • May have fewer problems with having erections than surgery. These develop more gradually. 	<ul style="list-style-type: none"> • The cancer may not be completely destroyed. • Have to go to radiation center for several weeks. • May have erection problems later on. • Rectum and bladder may become inflamed, so may have diarrhea, rectal bleeding, and urination problems. • May feel tired, weak during treatment. • Surgery may be more difficult if radiation is unsuccessful.
Internal "seed" radiation (Brachytherapy)	<ul style="list-style-type: none"> • May kill all the prostate cancer. • Not as hard on your body as surgery. • Do not need to be admitted to a hospital. 	<ul style="list-style-type: none"> • The cancer may not be completely destroyed. • May have problems having erections. • May have problems controlling bowels. • The procedure has not been used as long as the others. So, the chances of cure are less well known. • Rectum and bladder may become inflamed, so may have diarrhea, rectal bleeding, and urination problems.

Long term Side Effects of Treatment Choices

How to use this table

Read across to compare treatments.

Read down to learn how often side effects for each treatment happen.

	Watchful Waiting	Surgery	External "beam" radiation	Internal "seed" radiation (Brachytherapy)
Problems with erection (Impotence)	Rare*	60 in 100	45 in 100	45 in 100
Problems holding urine or leaking (Incontinence)	Rare*	9 in 100	Rare*	2 to 4 in 100
Passing urine: Painful or frequent	Rare*	Rare*	8 in 100	10 to 20 in 100
Loose bowels (Diarrhea)	Rare*	Rare*	8 in 100	8 in 100
Risk of dying from treatment (Death)	Rare*	Rare*	Rare*	Rare*

For the first 3 months after treatment many more men have impotence, incontinence, painful or frequent urination, and diarrhea as *temporary* side effects.

A 2005 study compared the side effects and long term quality of life 6 years following treatment for prostate cancer with the same ones found 2½ years after treatment. It showed that although the side effects of surgery appeared right away and then stabilized, the side effects of radiation and brachytherapy tended to change over time.

The numbers used in the table above come from many doctors, patients, and published articles. They are averages for patients of all ages. In general, younger patients may have fewer problems from treatment.

* Rare means less than 1 in 100.

Newer treatments

The treatments we have talked about and shown in the chart are standard treatments. Additional treatment choices are not listed because they are still being evaluated for safety and effectiveness. That is, the newer treatment methods have not been studied well enough to be considered standard.

- Cryosurgery (freezing the prostate) is a newer treatment many men have considered.
- Scientists are always looking for better ways to treat prostate cancer. They test new and old forms of treatment through research studies (clinical trials).
- You may wish to find out about or take part in these research studies. So ask your doctor about them.
- Newer treatments may or may *not* be covered by your insurance.

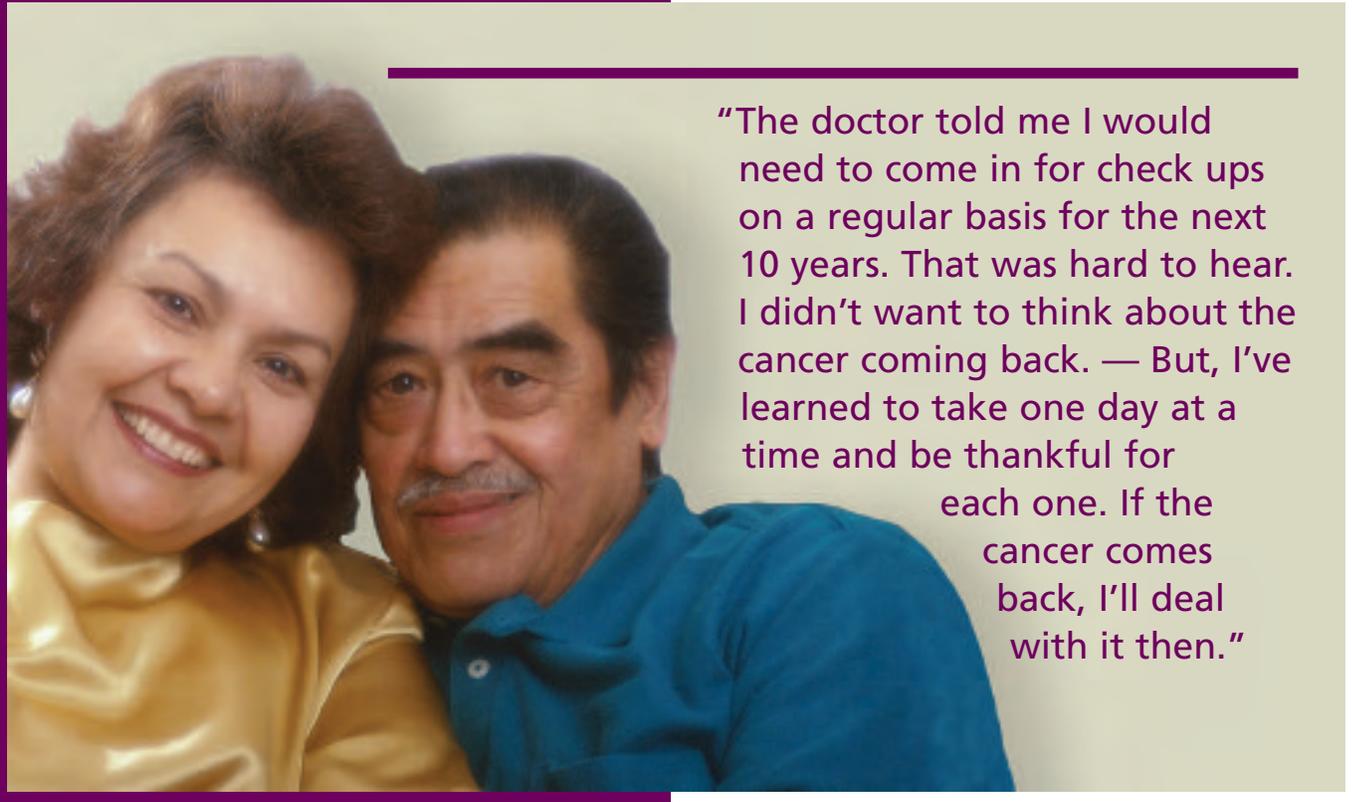
After Your Treatment is Finished

Making sure the treatment has worked

- After your treatment, you will have regular doctor visits and tests from time to time because prostate cancer can come back, even after treatment.
- During the office visit, you will probably have:
 - a **D**igital **R**ectal **E**xam (DRE) even if the prostate was removed during surgery
 - a PSA test
- Your doctor will continue to check your PSA after treatment. If your PSA is going up, this can be an early warning that the cancer is back.
- If all tests remain normal, the cancer is said to be in remission. That means the cancer cannot be found. But you still should have regular doctor visits and tests from time to time.

If your cancer returns

- Sadly, no treatment is foolproof. If the cancer comes back, it's generally more difficult to treat the second time around.
- If the cancer is still confined to the prostate gland area, your doctor may try some type of local treatment different from the first.
- If the cancer has spread beyond the prostate gland area, you would need to have a treatment that would affect the entire body, not just the area of the prostate.



“The doctor told me I would need to come in for check ups on a regular basis for the next 10 years. That was hard to hear. I didn’t want to think about the cancer coming back. — But, I’ve learned to take one day at a time and be thankful for each one. If the cancer comes back, I’ll deal with it then.”

Thinking About the Future: What Happens if My Cancer Gets Worse

What we have talked about so far: EARLY Stage Prostate Cancer

The treatments listed in this booklet, so far, are for men with *early* stage prostate cancer.

- *Early* stage prostate cancer is still confined *in* the prostate.
- It is cancer that has appeared not to have spread.
- It is cancer that may be easier to cure.
- The aim of treatment is to cure the cancer or to treat symptoms that may occur.
- Watchful waiting, surgery, and radiation are all *local* treatments. This means they just affect the prostate gland. They may work because the cancer is confined to the prostate and has not spread.
- In addition to local treatment, your doctor may suggest other treatment such as lowering male hormones.

What we have not talked about so far: LATER Stage Prostate Cancer

Some men (about 17 out of 100) will have cancer that has spread *beyond* the prostate when they first see the doctor. In some cases the cancer may come back after surgery or radiation. These are all considered later stage cancers.

- *Later* stage prostate cancer is *not* confined to the prostate.
- It is cancer that has spread *beyond* the prostate.
- It is cancer that is *not* so easy to cure, but may be curable.
- The aim of treatment is to control certain symptoms such as pain and trouble passing your urine.
- Treatments are *systemic*. That means they must flow through or affect your whole system. You may need them if cancer has spread to other parts of your body.

If you develop later stage prostate cancer, your medical team will talk with you about treatments for that stage of cancer.

A Choice and A Journey

We hope you now understand what you need to know to make the treatment choice right for you.

Here are the most important ideas we can share with you:

- Your treatment decision is a shared one between you and your doctor.
- The doctor best knows the details of the procedures and the likely outcomes.
- Only *you* know how you feel about the balance between possible cure and living with side effects.

Men who worry more about side effects often choose watchful waiting.

Men who worry more about living with cancer in their body would often choose radiation or surgery.

Think about what is most important to *you* as you make your decision.

Each choice has some risk. There are no sure answers.

Hearing that you have prostate cancer may shock or frighten you, your family, and your friends. These feelings are natural. They may change over time, as you learn about your diagnosis, make treatment decisions, deal with symptoms, and go on with your life. Men are often afraid to share their feelings or get help from a counselor if needed. If strong feelings are hurting you or your family, ask your doctor to suggest help.

Some say that dealing with a cancer is like going on a journey — one where you don't know how long it will last and how it might end.

It isn't easy, but others are with you to help.

We wish you the best journey possible.



Things to Ask Your Doctor

What treatment, or treatments do you recommend for me?

How does the rate of side effects in this booklet compare to the rate of side effects in your practice?

How likely is my cancer to come back in the next 5 years or 10 years?

How frequently will I have to see a doctor after being treated? _____

Will I have to have more tests? _____

Who can I talk with about problems holding urine or with having erections after treatment? _____

Where can I find a support group? _____

Does my age, or current health, indicate any treatment is better for me?

Things for You to Think About

My biggest worry about prostate cancer is: (Write down your main worry.)

My most important goal for treatment is: (Check the most important one.)

- Curing the cancer
- Curing any symptoms I may have
- Having the best possible sexual performance
- Having good bowel and bladder control
- Other _____

What I like the most and the least about each treatment is:

	Most	Least
Watchful waiting	_____	_____
Surgery	_____	_____
External beam radiation	_____	_____
Internal seed radiation	_____	_____

The treatment I am leaning toward is: (check one)

- Watchful waiting Surgery External beam radiation Internal seed radiation

A Review of Medical Words Used in This Booklet

B biopsy • Doctor snips a small piece of tissue, which is looked at closely under a microscope.

bladder • Pouch inside your body where urine is stored. When the bladder is full, you feel like you need to pass your urine.

bone scan • An imaging procedure to tell if prostate cancer has spread to the bones.

bowels • The long tube in the body that holds bowel movements.

brachytherapy • Type of internal seed radiation sometimes used to treat prostate cancer. The seeds are inserted through the area underneath the testicles.

C cancer • The general term for a group of diseases in which body cells start to grow out of control.

cancer grade • Best guess about how fast the cancer is probably growing (how aggressive it is). With prostate cancer, the grade is also called the Gleason Sum or Gleason Score.

cancer stage • Tells about how big the cancer is and about how much it has probably spread.

catheter • Tube used to drain the urine from the bladder. In men, the tube is put in through the penis.

clinical trial • Research studies that test new drugs or procedures with less well-known or unknown effects or side effects.

conformal radiation therapy • Conformal external beam radiation is a better way of directing the radiation to the prostate without spilling over to other tissues.

CT scan • An X-Ray procedure that uses a computer to look at many areas of the body. It can be used to tell if prostate cancer has spread.

D diagnosis • When a doctor figures out what is wrong with a patient, using information the patient gives, a physical exam, and test results.

Digital Rectal Exam (DRE) • When a health care provider inserts a finger in the rectum to feel the prostate.

E erection • When the penis gets hard.

external beam radiation • A treatment using a radiation source outside the body to treat cancer.

G Gleason Sum • Grade of a prostate cancer resulting from looking at a biopsy sample through a microscope. Also called the Gleason Score or Cancer Grade.

H hormone • A natural substance produced in one part of the body that affects cells elsewhere in the body.

hormone lowering therapy • Cancer treatment that involves lowering or blocking male hormones.

I incontinence • Can't control the flow of urine from the bladder. Not being able to control passing your urine (pee).

impotence • Can't have an erection; penis doesn't get hard.

in remission • Cancer is not found after treatment.

internal seed implant (brachytherapy)

• Radiation therapy in which a radiation source is placed in the prostate.

L laparoscope • A lighted tube used to help remove the prostate through the abdomen.

local therapy • Treatment that affects a tumor and the area nearby.

lymph nodes (glands) • Small areas in the body where germs or cancer cells are trapped. Lymph nodes also have special cells that help fight infections. Some of these nodes are often removed during surgery.

M metastasis • Prostate cancer that has spread to distant places in the body, like bone or liver.

MRI • A non-X-Ray procedure that uses a computer to look at many areas of the body. It can be used to tell if prostate cancer has spread.

N node • A short-hand way of saying lymph node.

O oncologist • A doctor who specializes in treating cancer. Radiation Oncologists treat cancer with radiation. Medical Oncologists use hormones and drugs to treat cancer.

P prostatitis • Inflamed or infected area of the prostate.

Prostate Specific Antigen (PSA) • A substance made by the prostate that can be measured with a blood test. A high level in the blood may or may not indicate prostate cancer.

R radiation therapy • Treatment using radiation to destroy cancer.

radical prostatectomy • Surgical removal of the prostate from the patient.

rectum • Opening in the bottom where the bowel movements come out.

robotic surgery • A radical prostatectomy where the doctor is assisted by a device that replaces his/her hands with robotic hands and magnifies the surgery through a lighted tube (laparoscope).

S scrotum • In men, the pouch of skin that contains the testicles (balls).

second opinion • Term used by insurance and medical experts to mean asking another doctor to review your case and the treatment proposed for you.

seed implant (brachytherapy) • Radiation therapy in which a radiation source is placed in the prostate.

semen • Male sex fluid.

seminal vesicle • A small sac attached to the prostate that holds sperm. Cancer may spread there.

stage • With cancer, the stage describes how much a cancer has probably spread.

surgery • Complete removal of the prostate using a traditional surgery, laparoscopy, robotic surgery, or any other means.

T testicles • Male sex glands (balls).

tumor • An abnormal mass of tissue, sometimes used to talk about cancer.

U urethra • A tube that carries urine or semen to the outside of the body, through the penis.

urologist • A surgical doctor who specializes in diseases of the urinary and male sex organs.

A Place to Chart Your Progress

The following table is a place to write the results of your follow-up studies.

DATE	PSA	GRADE	STAGE	CT SCAN	BONE SCAN

Education and Support Groups: Learning from Others

Ask your doctor about local groups that you and your family can talk with. They are facing these same decisions, and are living with cancer. For support groups, you can also contact Us TOO at 1-800-80-US TOO or 1-800-808-7866 (www.ustoo.org).

To reach experts for more information you may contact:

- The American Cancer Society 1-800-ACS-2345 (www.cancer.org and enter your zip code).
- AFUD (American Foundation for Urologic Diseases) at 1-800-828-7866 (www.afud.org).
- National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (www.nci.nih.gov).

If you call, you don't have to give your name on the phone.

Information about prostate cancer screening is available on these Centers for Disease Control and Prevention (CDC) website pages:

- Prostate Cancer Screening, A Decision Guide
<http://www.cdc.gov/cancer/prostate/publications/decisionguide/index.htm>
- Prostate Cancer Screening, A Decision Guide for African Americans
<http://www.cdc.gov/cancer/prostate/publications/aadecisionguide/index.htm>
- La Detección del Cáncer de Próstata: Una Guía para Hispanos en los Estados Unidos
http://www.cdc.gov/cancer/prostate/prospdf/prostate_cancer_spanish.pdf

Where to get more copies of this booklet

To get more copies of this booklet or the same information in an audio format (CD and cassette) from the Michigan Cancer Consortium

- Call toll free: 1-800-249-0314 or
- Visit www.prostatecancerdecision.org on the Internet.

Materials are free of charge to Michigan residents and organizations. Orders at no cost from outside the state of Michigan are limited to 20 booklets, 1 audio set, and 1 poster. Out of state orders over this amount and all out of country orders can be filled at cost by calling 1-800-249-0314.

This publication was developed in response to a priority of the Michigan Cancer Consortium, under guidance of the Prostate Cancer Action Committee. Their efforts were supported in part by the Michigan Public Health Institute, the Michigan Department of Community Health, and the Agency for Healthcare Research and Quality with funding from the Centers for Disease Control and Prevention. The contents of the publication do not necessarily represent the official views of the Centers for Disease Control and Prevention. The authors are indebted to Drs. Martin Sanda, David Wood, James Hayman, Howard Sandler, Kenneth Pienta, and Susanne Quallich, NP and the patients who reviewed the material and suggested changes.

These materials may be duplicated only in their entirety and only for users' internal non-commercial purposes. All duplication copies must contain authorship credits as they appear on the original materials. For more information, call the Michigan Cancer Consortium at 877-588-6224.

Last revised, March 2008.

Credits

MICHIGAN CANCER CONSORTIUM PROSTATE CANCER ACTION COMMITTEE (MCC PCAC)

Ann Arbor Veteran Affairs:

Angela Fagerlin, Ph.D.*

Community Health Advocate:

Robert B. Johnson, M.H.A.

Robert Knobel, P.E.

Great Lakes Cancer Institute:

Ray Demers, M.D., M.P.H.

Henry Ford Health System:

Lisa King, M.H.S.A.

Ashutosh Tewari, M.D.

Hospice of Michigan:

Jeanne Parzuchowski, M.S., O.C.N., R.N.

Hurley Medical Center:

Jenny LaChance, B.A.

Kay Taylor, Ph.D.

Michigan Department of Community Health:

Carol Callaghan, M.P.H.

Harry McGee, M.P.H.

Michigan Public Health Institute:

Carol Garlinghouse, M.S.N., R.N.

Polly Hager, M.S.N., R.N.

Judith A. Suess, M.D., M.P.H.

Richard Wimberley, M.P.A.

May Yassine, Ph.D.

Michigan State University:

Vence Bonham, J.D.

Ray Demers, M.D., M.P.H.

Larry Hembroff, Ph.D.

Margaret Holmes-Rovner, Ph.D.*

David Rovner, M.D.*

Prostate Cancer Coalition of Michigan:

Lonnie D. Johnson, M.S.W., C.S.W.

Brig. Gen. Michael J. Rice, Ret.

Jerry Sims

University of Michigan:

Rodney L. Dunn, M.S.

Maha Hussain, M.D.

Willie Underwood, M.S., M.D.

Mark J. Velarde, M.S.

John T. Wei, M.D., M.S.*

THE CLEAR LANGUAGE GROUP

Janet Ohene-Frempong, M.S.*

Sue Stableford, M.P.H., M.S.B.*

Arab Community Center for Economic and Social Services (ACCESS)

Adnan Hammad, Ph.D.

Wayne State University

Wael A. Sakr, M.D.

UNIVERSITY OF MICHIGAN**COMPREHENSIVE CANCER CENTER,****HEALTH MEDIA RESEARCH LABORATORY (HMRL)**

Alan Bliss, B.A.

Pamela Marz, M.P.H.

Lesla Monroe-Gatrell, B.F.A.

Marcus Sarkesian, B.S.E.

Ed Saunders, M.S.

Victor Strecher, Ph.D.

*Principal authors



PCIG

The Prostate Cancer Information Group
The Cincinnati Ohio chapter of Us TOO International

*The Cincinnati PCIG Supplement to
the Michigan Cancer Consortium (MCC)
booklet of March 2008 titled:*

Making the Choice

Deciding What to Do About
Early Stage Prostate Cancer

Contents:

- Part 1 – Information to help you make an informed decision.
- Part 2 – Cincinnati services and resources.

The complete *Making the Choice* booklet can be viewed and downloaded in three languages and in audio from MCC's website: www.ProstateCancerDecision.org

PCIG is an all volunteer group of Prostate Cancer survivors. Others have helped us learn about this disease. Their information plus our own study and experience are the foundation of this supplement.

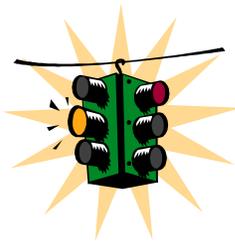
Part 1 – Information to help you make an informed decision.

DISCLAIMERS:

- 1. The information in this supplement is our best collective opinion. It is for educational purposes only. Patients should never disregard medical advice nor delay seeking medical advice while reviewing educational information.**
- 2. The Michigan Cancer Consortium booklet, on which this supplement is based, is copyrighted. This supplement is not copyrighted. MCC has neither approved nor disapproved the contents of this supplement.**

Welcome

Learning that you have Prostate Cancer is usually frightening. We know. We have been there. We are Prostate Cancer survivors who want to make dealing with this topic a bit easier for others. We have found that this is a complex disease, so we want to offer you information that is clear and unbiased to assist your decision making. Our goal is that the knowledge gained from this supplement empowers you to manage this disease with confidence.



A frequent comment heard at our meetings is that survivors wish they had taken more time to learn about this disease BEFORE deciding on a course of action. Far too often men find themselves quickly zeroing in on a treatment plan then later regretting that decision.

Over the years, we have learned this disease is unlike other medical situations or even other forms of cancer. Some of the key differences are, for Prostate Cancer:

- Most cases are SLOW GROWING. Treatment can often be deferred or completely avoided.
- SIDE EFFECTS from treatment are not always fully understood by patients before treatment.
- Because different treatments can produce similar survival rates, the PATIENT, not the doctor, may be better qualified to make the final decision of what to do.
- The prostate is a SEX ORGAN. Your relationship with your partner may be affected by your decision. Analysis of treatment side effects and good communication is important
- This is COMPLEX. There are many treatment alternatives. They are challenging to compare.
- The science involved is DYNAMIC. Medical options are evolving at a very rapid pace.

This supplement provides additional options beyond those given in the MCC booklet to provide considerations so you may determine what is best for you.

This process starts by using data from your biopsy report and other factors that allow you to do a Risk Assessment. With your resulting risk level and some personal information you can evaluate options that are appropriate for your situation. For example, men with a “Low Risk” Risk Assessment (which is the majority of cases) will be encouraged to consider “Active Surveillance”. This may let you postpone or avoid medical treatment and the sometimes serious struggle with treatment side effects.

Risk Assessment

One of the first widely-adopted approaches to risk stratification is a 3-level classification published in JAMA in 1998 by Dr. Anthony D’Amico, Chief of Radiation at the Harvard Medical School. This proposes that we should regard Prostate Cancer as not one, but three different diseases. The patient should know which type he has, and consider the appropriate plan of action, such as:

Low Risk ⇒ Consider Ways to Defer or Avoid Medical Treatment

Medium Risk ⇒ Consider the Medical Treatment Option that is Best for You

High Risk ⇒ Consider Aggressive Treatment

By one count, over a hundred Risk Assessment tools using formulas, calculators, and nomograms have been proposed, but many appear to be flawed or biased. Our group prefers the Prostate Cancer Research Institute tool called CAPRA (Cancer of the Prostate Risk Assessment)¹. It is simple. You assign points, compute your score on a 0-10 scale, and then find your risk level below.

Variable	Level	Points	Variable	Level	Points
PSA	≤6	0	T-stage	T1/T2	0
	6.1-10	1		T3a	1
	10.1-20	2	% of biopsy cores positive	<34%	0
	20.1-30	3		≥34%	1
	>30	4			
Gleason (primary/secondary)	1-3/1-3	0	Age	<50	0
	1-3/4-5	1		≥50	1
	4-5/1-5	3			

CARPA Score of 0 – 2 = LOW RISK (Go to page 4)

CARPA Score of 3 – 5 = MEDIUM RISK (Go to page 6)

CARPA Score of 6 – 10 = HIGH RISK (Go to page 8)

Example: A PSA of 6.5 (1 pt), a Gleason of 3+3 (0 pt), T1 or T2 staging (0 pt), three of twelve cores positive (0 pt), and 59 years (1 pt) gives a CAPRA score of 2. This man is at Low Risk.

¹ For more about the background of this tool, see *Understanding and Applying Risk Assessment for Prostate Cancer*, PCRI Insights, November 2010, Vol 13: No 4, pages 3-7 by. Matthew R. Coopenburg MD, MPH. A copy of this article is available by email from JGolan@ProstateCincinnati.org.

For men with **LOW RISK** prostate cancer

Most everyone who learns they have cancer would like to GET RID OF IT, and the sooner the better. The very idea of deferring treatment may seem like a questionable strategy that just allows the cancer to grow. That fear is a key factor that leads to 50,000 prostates being surgically removed each year in the US even though 40,000 of these didn't need to be.² Those 40,000 may have experienced needless treatment side effects.



The good news is that you have time to think this through. Your cancer did not develop overnight and it doesn't need to be dealt with immediately. While calculating your Risk Assessment on the previous page only takes a few minutes, this phase is different. Take a deep breath and make a commitment to take the time needed, usually a few months, to learn about your situation and your choices.

Watchful Waiting is discussed on pages 10 and 11 of the MCC booklet. This is a strategy for delaying medical treatment while doing some monitoring. While that is a good strategy for some situations, for others a more proactive means of delaying treatment may be more suitable. Active Surveillance is a strategy that encourages men do a number of things to fight the cancer while more closely monitoring to see if conditions improve, remain the same, or deteriorate. Some men on Active Surveillance report that they have become cancer free after a few years.

STEP 1 A great way to begin learning about Active Surveillance is to watch five short videos from the Prostate Cancer Forum of Orange County, California. Their series explains this topic clearly and shares the experience of three diagnosed men. See them at www.active-surveillance.com

STEP 2 Most men weigh various factors to find their own answer to the question *Should I Be Treated?*. In addition to your Risk Assessment, other key factors include

- Do I know enough to make an informed decision? Your study should include non-treatment options, treatment options (see Medium Risk comments on page 6), and treatment side effects.
- As I consider non-treatment options, can I handle the emotions of waiting? What is my tolerance for the mental anxiety of living with cancer?
- As I consider treatment alternatives, what is my age and medical condition aside from Prostate Cancer? Am I likely to live long enough to benefit from treatment?

The basic idea is to gather information while these considerations churn in your mind for a while. It can be helpful to talk with several people who have this disease. Ask questions and take good notes. Interview some doctors. Have some deep conversations with your partner. Consider the protocols for Active Surveillance (see next page) and assess your likelihood of being faithful to them. If you decide not to be treated, you can always change your mind if your condition worsens or better treatment options emerge. If you decide to be treated you become committed. So take your time and lay the foundation for your future based on good information that will give you peace of mind.

² From *Invasion of the Prostate Snatchers*, by Scholz, Mark, MC, and Blum, Ralph, 2010, Published by "Other Press", first edition. Available from Amazon.com ASIN B003D8J5Q.

Recap of NON-TREATMENT Alternatives

Do Nothing

COMMENT: This may be a reasonable choice if you are LOW or MEDIUM risk and your life expectancy is short (possibly under 10 years).

Watchful Waiting

THE **Watchful** PART: You and your doctor make plans for periodic monitoring tests.

COMMENT: This may be a reasonable choice if you are LOW risk and either older or have serious health problems. You avoid dealing with a treatment process and all side effects. You can change course if your conditions change.

Active Surveillance

THE **Active** PART: To help your body fight prostate cancer, make lifestyle changes such as:

- Use a Mediterranean heart healthy diet (Avoid red meat, egg yoke, and dairy fats. Increase fish, fruit, vegetables, and omega 3 oils.)
- Significant exercise (An hour or more a day of vigorous exercise is thought to be helpful)
- Weight control (Restrict caloric intake, especially at supper or before periods of low activity)
- Stress control (Reduce tension and anxiety. Be a happier, more loving person)
- Consider certain Vitamins and Supplements (Use blood tests to determine your needs)

THE **Surveillance** PART: You and your doctor decide on a test regiment such as getting a PSA and “Free PSA” every 3 months + PCA-3 and DRE every 6 months + MRI Spectroscopy or Color Doppler Ultrasound each year + a biopsy at one year and every 2-3 yrs thereafter. This close monitoring is so your disease doesn’t sneak up on you.

If your condition gets better, you can lessen this regiment. Some people beat this disease just by making lifestyle improvements. On the other hand, if your condition worsens, you can consider treatment when needed. Delaying treatment can avoid years of dealing with treatment side effects. Delaying treatment may also position you to be a candidate for one of more than twenty new (high technology) therapies being worked on in labs. Some of these offer the hope to CURE prostate cancer completely.

COMMENT: This may be a reasonable choice if you are LOW risk and can commit to the protocols needed to be successful.

For men with MEDIUM RISK prostate cancer

It is possible that one of the options for the Low Risk men may be the most suitable for you, and you are encouraged to look over the preceding two pages to assess this for your situation.

It is also possible that treatment plans for High Risk men may be the most suitable for you, and you are encouraged to review that section of this supplement as well.

For most men in the Medium Risk category a specific treatment plan may be the most suitable plan for you. We have found that selecting a plan and the doctor to implement your plan is rather complex. Study is needed to learn about the options so you can make the best decision. It may be helpful to promise yourself that you will not rush to select a treatment until you are satisfied that you have done your homework and are fully confident in your decision. (This is because once you select and undergo a treatment, you can never undo that decision.) The activities below are not sequential steps, but to be pursued more or less in parallel to assist you in developing your plan.



No one said this was simple.

ACTIVITY “A” Read pages 12 – 17 of the *Making the Choice* booklet. This gives a good description of popular surgery and radiation choices. It also does a great job presenting the side effects. (Good side effect data is hard to find elsewhere³, and this a key reason why we like this resource.) While we concur with the information in the booklet, we want to expand on a few points.

- There are more options for radiation than are covered in the booklet. This includes both the type of radiation⁴ and use of combination external and internal treatments⁵. A significant number of men select their plan from among those expanded choices, so you may find it helpful to learn more about them. One place to learn more about the various types of radiation treatment and a comparison of treatment options is a chart at <http://dattoli.com/prostate-cancer-results/interactive-treatment-chart/i/15>
- The likelihood of being cured from a treatment choice is not covered. This has been a tough topic to nail down because a) surgery and radiation treatments use different cure definitions, b) cure is linked to the extent of the disease when treatment starts, and c) medical facilities and doctors have different equipment and experience. Item c) results in different track records, and usually only the best publish their data. We are working with national sources to resolve this problem. Preliminary (and quite different) information is available by email from Lisa Grimm, Research Coordinator, Prostate Cancer Treatment Center at lisa@ProstateCancerTC.com and from a patient group at www.RCOGPatients.com
- The learning process to digest all this information and move toward an informed decision is not covered. We do not profess to be experts in this, but we believe that the following steps will help.

³ For more on this see a New England Journal of Medicine report called *Quality of Life and Satisfaction with Outcome Among Prostate Cancer Survivors*. at <http://www.nejm.org/doi/full/10.1056/NEJMoa074311#t=articleTop> Table 4 of that report is a good summary of treatment side effects.

⁴ Differences include both the precision of the delivery system and the type of beam. For example “Photon Radiation” is a different type beam. While quite expensive, it is thought to have fewer side effects.

⁵ Some people believe that the combination of external and internal is better because the combined dosage is less than either of the single type treatments alone. It may therefore have good effectiveness with fewer side effects.

ACTIVITY “B” Our experience suggests that to make a knowledgeable decision with confidence, these elements are important to the process:

1. You need details of the treatment choice. This includes a description of the procedure, the expected pain, near and long term recovery expectations, side effects, medical risks, and cost. Make notes of what you are told when you discuss this with your doctors.
2. Make a written comparison of Cure Rate and Side Effect information received from literature and your doctors. Don't be shy to ask questions. You only get to make a treatment choice once, so gather your data carefully and make your analysis wisely.
3. How does your doctor's experience stack up against national data? Start a journal for questions and answers. Some questions to ask are: a) How much training on this procedure did you receive before you started to treat patients? b) Will your procedure be performed by you or a resident? c) How many patients have you treated? (Practice makes for better results. One robotic surgery analysis indicates results will be better after a doctor has completed 300 procedures.) d) Do you keep patient records, and if so what does your database say about cure rates and side effects. Where have those records been published? More questions can be found in the Newly Diagnosed area of www.UsTOO.org. If you do not like or trust the answers, consider going to a different treatment center. 
4. Your own situation is critical to determine how much treatment you really need. We are all unique and your personal situation should affect your choice. Some factors to stir into the mix are:
 - ▶ Your Risk Assessment
 - ▶ Your overall health and life expectancy
 - ▶ Your tolerance for pain
 - ▶ Your acceptance of the Cure Rate predictions
 - ▶ Your partner's perspective
 - ▶ Your tolerance for the treatment Side Effects

ACTIVITY “C” While the intellectual knowledge in the previous activity is needed, it also is important to reach out to others to form a perspective on the emotional side of the situation. Talking with prostate cancer survivors is a valuable way to gain that insight. If you live close to a chapter of Us TOO International, go to a meeting and share where you are in your journey and ask for comments. You can find a directory of local chapters by going to www.UsTOO.org and click on “Find a Support Chapter Near You”. If you are not close to a Support Chapter, look into Us TOO's options for “On-line Communities”. If possible, you may want to use both resources, as each has unique advantages and can be VERY helpful in providing insights, addressing your questions, and alleviating concerns.

ACTIVITY “D” Before and after treatment there are things you can do to minimize the impact of side effects. Some useful items include:

- Get in shape. Lose weight, and tone muscles
- If planning surgery, be sure that you do the prescribed Kegel exercises beforehand
- If planning radiation, be patient as the side effects can take a while to develop and years to heal.
- Some treatment plans will reduce libido. Consider penile exercises to preserve blood flow
- Treatments (other than “Seeds”) may cause genital shrinkage. To learn about managing this, see:
 - (Radiation) <http://askdrmyers.wordpress.com/2011/03/09/your-penis-after-rt-adt/>.
 - (Radiation) <http://askdrmyers.wordpress.com/2011/02/02/penile-shortening-revisited/>.
 - (Surgery) <http://askdrmyers.wordpress.com/2011/01/05/penile-shortening-post-rp/>.
 - (Hormonal) <http://askdrmyers.wordpress.com/2010/11/24/sex-on-hormonal-therapy/>.
- If erection problems occur (*very common*) talk with your partner and get help. There are options.
- Consider doing some of the “Active” items of the “Active Surveillance” plan.
- Don't struggle alone. There are lots of resources out there. Reach out and use them.

For men with HIGH RISK prostate cancer

This situation is serious and achieving a cure is not easy, but it is possible. You will probably need a medical assessment to determine the complete course of action. Since this cancer is sometimes more aggressive, men in this category should choose their plan relatively soon before their disease progresses further, and anticipate aggressive treatment,

If the cancer has not spread to your bones and you are otherwise in good health and with a reasonable life expectancy, many doctors agree that you should consider some form of combination therapy.

Combination therapy, that is designed to kill cancer cells both inside and just outside the prostate, can take many forms:

- Radioactive Seeds before Intensity Modulated Radiation Therapy (Seeds before IMRT)
- IMRT before Seeds
- Temporary High Dose Rate (HDR) “internal radiation” before IMRT.

Some of these treatments, as well as others, can also be augmented with hormonal depletion therapy. Although hormonal depletion has side effects which tend to eventually go away, they can be an issue during treatment. High risk patients need to be concerned with selecting a treatment with reduced side effects, with or without hormonal depletion therapy.

Treatments such as Surgery and Seeds Only are typically not recommended for men with high risk prostate cancer.

One final suggestion is to inquire about the status of experimental therapies (medical trials) that may be available. Some of those in the laboratory, if approved for clinical trials, may have higher cure potential and much fewer side effects making them attractive alternates to the typical treatment plans. Just be careful that you understand that some clinical trials provide placebos instead of treatment meds to some of the participants in order to judge the differences. You may not receive any treatment if you happen to be selected as one of the placebo patients.

<p>We have done our best to make this supplement both clear and useful. That doesn't mean it can't be improved. We welcome your feedback to make this better. Please send your comments to GGardner@ProstateCincinnati.org</p>

Part 2 – Cincinnati services and resources.

If you live in our local area, you are fortunate because we have an active volunteer group that offers our PCIG members several resources to assist you and your partner.

- A website operated by the Prostate Cancer Information Group of Cincinnati, Ohio
- Monthly Man-to-Man meetings to understand and discuss your issues
- Personal Journey experience stories, useful reports, and news alerts sent by e-mail.
- Monthly Educational Meetings for you and your partner
- A lending library of excellent books about this disease and the side effects
- Medical, Pharmaceutical, and Nonprofit Literature, DVD's, and Newsletters
- Access to the full support and services of The Wellness Community in Blue Ash and Northern Kentucky. (This is part of the Cancer Support Community)
- Links to trusted national resources, vetted websites, and national on-line forums
- A series of there New Member Packages that recap details of what we have to offer.
- A Private Panel to relay your unique questions to our membership for personal replies
- A professional quality Community Outreach PowerPoint Presentation for your group
- Access to locally produced informational material such as:
 - a) A PowerPoint presentation about Photon therapy
 - b) A PowerPoint summarizing the Prostate Cancer Research Institute's current treatment state-of-the-art and in depth information about non-treatment options
 - c) A booklet to help deal with Sexual Intimacy after Prostate Cancer
 - d) Nutrition suggestions in the form of prostate healthy recipes
 - e) The latest statistical summary of Cure Rates
- [*Under construction*] A consultation network of prostate cancer survivors organized by experience and willing to discuss your questions by phone on a one-to-one basis.

All of our services are totally free, so take advantage of them.

To engage us, you may:



Visit www.ProstateCincinnati.org



Join us any second Wednesday at 7 p.m. at
The Wellness Community, 4918 Cooper Road



Master

Call Tom Young, (513) 509-5040



Fire off an e-mail to Jim, our Mail

JGolan@ProstateCincinnati.org

