



**"Blessing the Journey"**

# Making the Choice

## Deciding What to Do About All Stages of Prostate Cancer

"Many have faced the same tough choices you face now. We talked with family, our doctors and others we trust. We each made our choices. You can too!

This booklet will help you make your choice".



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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 Tribal Elder Men Have Said



“Blessing the Journey II”

“When I first found out I had prostate cancer, confirmed by my biopsy, I didn’t hear a word after that. All I could do was think I was gonna die! My wife didn’t even know what prostate cancer was but I’m glad my wife was there with me to listen. We did not mess around. My Doctor ordered new testing to determine a baseline. It was probably harder on my wife than it was on me.”



“Testing the Waters”

“When my doctor told me I had prostate cancer it was an eye opener. My first thought was “I am gonna die!” I researched this as much as possible. I signed a Living Will, I wanted to make it easier on my people. Family and my doctor convinced me to take medicine and we now keep a close eye on it. I stay on top of my physical and mental health.”



“Reflection - Male Moon”

“My wife insisted I get a physical. I told her there is nothing wrong with me and I never get physicals. I feel like a million bucks. I ended up going and three days after my physical they called me up and said they had information for me. So I went into the doctor and that is when I first found out. I had no idea even what prostate cancer was. I should be sick. Yea, I couldn’t believe it, I didn’t think anything was wrong with me.”

## 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 possible results of these 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 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. Contact us at 877-588-6224 or [www.michigancancer.org](http://www.michigancancer.org).



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

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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 added complications that you could have avoided if you didn't need treatment.
  - 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.)
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Don't be pressured. Read.

Ask questions. Think. Then decide.

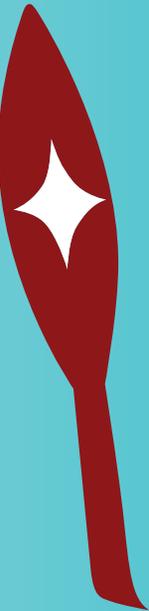
- Each man is different. There is no right or wrong decision.
  - You can get a second medical opinion. Ask if your tribal clinic or insurance pays for it.
  - Try to make the decision that is best for you — one you can live with.
- 

"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."



**"Inner Reflections"**



# 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 (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 of 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

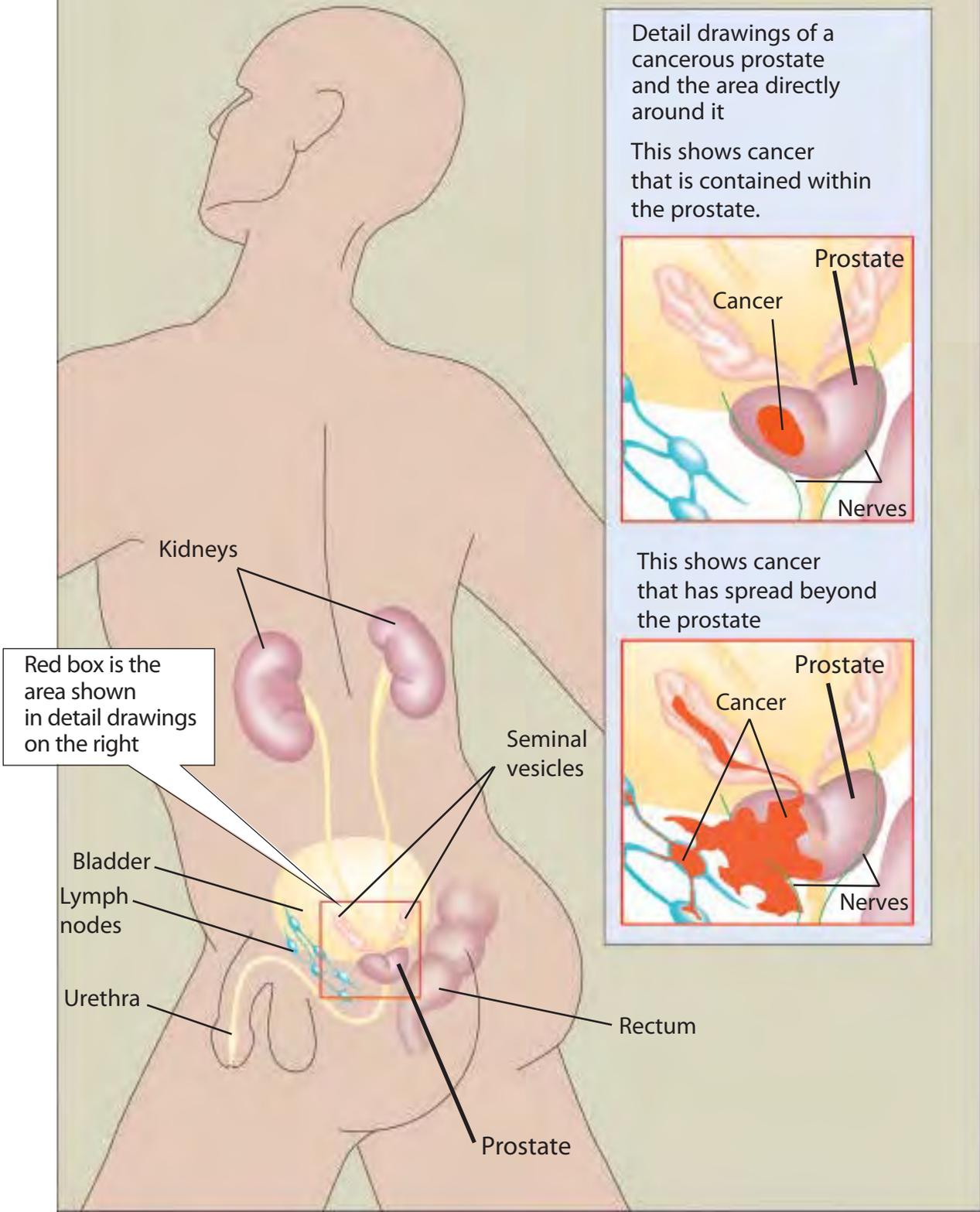
**Lymph Nodes:** Small glands that filter germs and are next to the prostate.

**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.



# 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.

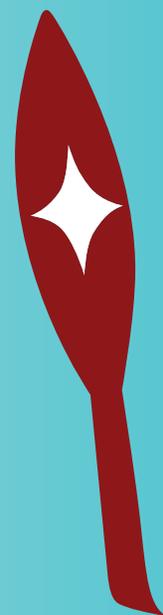
And then, check which statement is true for you.

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 probably not spread to other parts of the body.
	Stage B	Stage T2	The tumor is large enough for a doctor to feel. It has probably not spread 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.



**"The Journey Together"**

"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."



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## 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 in Native Americans is statistically even with Hispanics, Asian Pacific Islanders, and Whites. However, treatment may be equally successful for all groups if given the same care.

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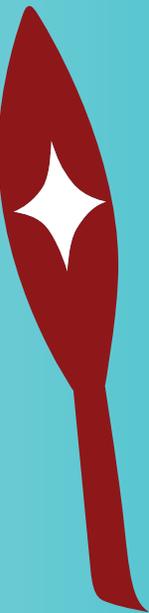
## What other people may have to say

### 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 tribal clinic or 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.”



“Salish Shaman”



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## 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).

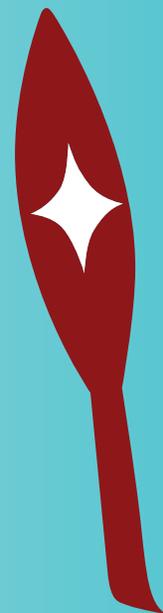
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## How this treatment may cause problems

- 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.



**"Male Sun Setting"**



# 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.



**“Pathways of Change”**

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“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.”



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## 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.

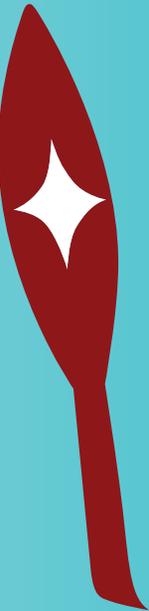
The risk of being impotent depends on a few things:

  - 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.”

**“Frogs Song - Regeneration of Spirit”**



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## 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:

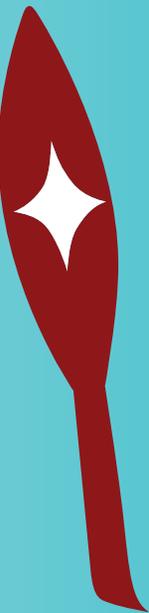
- Medicine that helps with erections.
- Vacuum device.
- Injections into your penis.
- Surgical implant.

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.

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

# 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 2.5 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 tribal clinic or 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 Digital Rectal Exam (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 fool proof. 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.”

“Let There Be Light”

# 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.



**“Sorrows Moon”**



# 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.

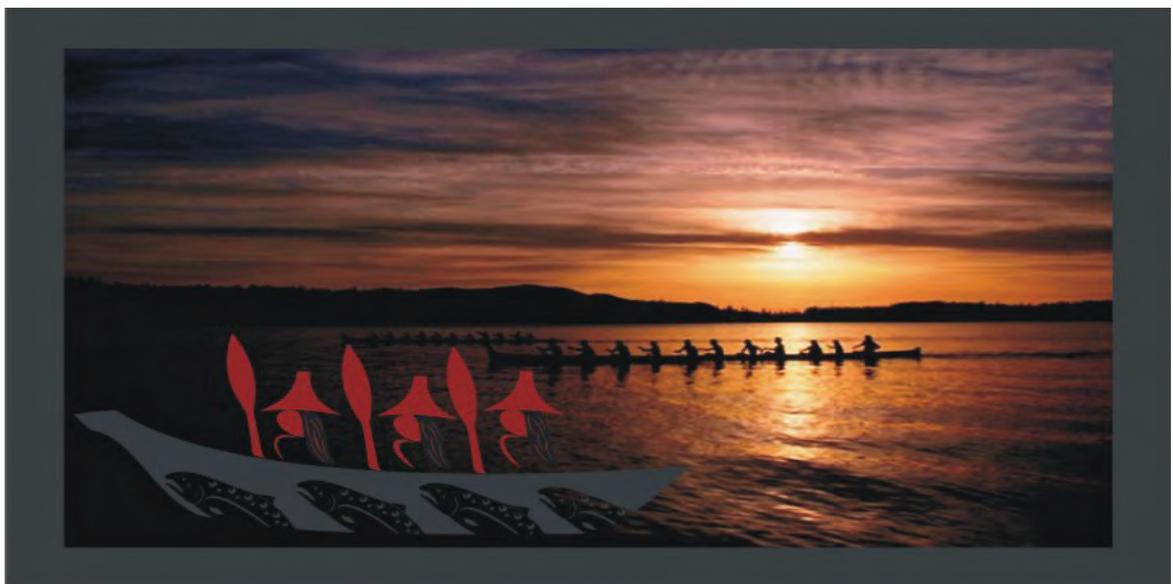
Men who worry more about side effects often choose watchful waiting. Men who worry more about living with cancer in their body would often choose radiation or surgery. Think about what is most important to you as you make your decision.

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.



**“The Journey”**

# 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 (Write down your main worry.)

My biggest worry about prostate cancer is:

\_\_\_\_\_

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

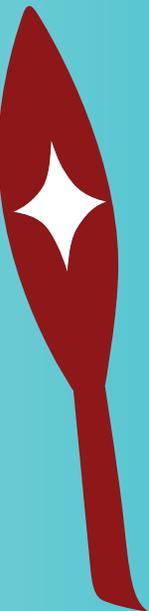
- Curing the cancer
- Curing any symptoms I may have
- Having the best possible sexual performance
- Having good bowel and bladder control
- Other \_\_\_\_\_

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 you need to pass your urine.

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

bowel • 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 tissue.

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.

D\_igital R\_\_ectal E\_xam (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.

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**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.

P\_rostate S\_pecific A\_ntigen (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.

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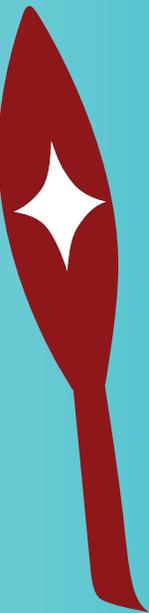
**T** testicles • Male sex glands (balls).

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 SPIPA/Informed Decision Making Regarding Prostate Cancer Treatment for Native Americans Project at 1-800-924-3984/ 1-360-426-3990 ([www.spipa.org](http://www.spipa.org)) or Us TOO at 1-800-80-USTOO or 1-800-808-7866 ([www.ustoo.org](http://www.ustoo.org))

To reach experts for more information you may contact:

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

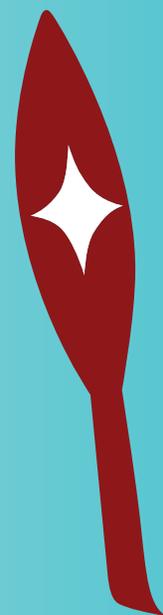
If you call, you don’t have to give your name on the phone.

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](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 in the Native American version contact SPIPA/Informed Decision Making Regarding Prostate Cancer Treatment for Native Americans Project at 1-800-924-3984 / 1-360-426-3990 or [www.spipa.org](http://www.spipa.org). 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](http://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.



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