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.”
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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 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 about treatment choices and coped with having prostate cancer. 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 men often die from other things first.

It’s not easy to choose the best treatment. Even the doctors don’t always agree.

There are 3 standard treatments for early stage prostate cancer: observation, surgery, and radiation.

Observation is just what the name says. Your doctor keeps a close watch on you at regular checkups. But, no surgery or radiation treatment is given to get rid of the cancer unless it starts to grow or cause problems. This is called Watchful Waiting if you and your doctor decide to only treat the cancer if it seems to be causing you symptoms. Active Surveillance [sir VAY lents], another form of observation, is when you and your doctor keep a close watch on the cancer and when it seems to be growing (or at any time), you can choose another treatment. Both of these options help you avoid some of the side effects of other treatments.

Surgery and radiation are two other treatment choices. 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 5 years, after observation, surgery or radiation, is about the same.

What does the best research say to do?

It is still not clear. Here’s why:

Two important studies show different results. A 2014 Swedish study showed an improvement in overall survival and in limiting cancer progression and spread with surgery compared to watchful waiting after more than 10 years of follow-up. A 2012 United States study – called the PIVOT study - compared surgery and watchful waiting and did not find a difference in survival. The reasons for the different results are not clear.
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 29 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.
- Include your partner (if you have one) during your visits to the doctor and during the decision process. If you approach making the decision as a team, it will be easier to support each other as you live with the decision.

“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 during ejaculation.

The prostate makes another substance important to you right now called PSA (Prostate Specific Antigen). 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, mainly the lymph nodes and seminal vesicles.

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 had a biopsy and possibly other tests to find out if you have prostate cancer. If you have cancer these tests give information about the type of cancer it is. But these tests are not perfect. When you get your test results from your doctor, it might help you to write down the information on the next few pages.

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 observation, 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 Score or the Gleason Sum.

- When you had a biopsy, doctors removed some cells from your prostate. Then, they use a microscope to see how fast the cancer cells seem to be growing.

- Based on what they find, they grade the tumor. Then they give you a number called the Gleason Score. It is a best guess of how fast your cancer might be growing. But it is not a perfect guess. The Gleason Score ranges from 6 to 10.

Write your Gleason Score here. [ ]

- If your Gleason Score was 6, the cancer is likely to grow slowly.
- If your Gleason Score was 7, the cancer is likely to grow at a medium rate.
- If your Gleason Score was 8, 9, or 10, the cancer is likely to grow fast.
- Lower Gleason Scores (2, 3, 4 or 5) were used in the past to indicate that the cancer is likely to grow slowly. They are not used any longer.
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.

- The system of letting you know the cancer stage 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).

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 my tests

What the Stage Means

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| Early stage
  [Cancer only in the prostate itself — what this booklet is about] | Stage T1 | The tumor has **probably not spread** to other parts of the body. |
| | 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 (Advanced)
  [Cancer outside the prostate] | Stage T3/T4 | The tumor **has spread** to tissue next to the prostate. |
| | 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 (observation, 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 Score)
   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 more 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 Score, and the Stage meant about my cancer.

My wife came to doctor’s appointments with me. She was a 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 more active treatment, even if they seem to have a slow growing tumor.
     - They want the cancer treated no matter what and they are willing to live with the side effects.
   - Other men want to wait and watch while keeping their treatment options open if the cancer starts to grow. They are more concerned that surgery or radiation may mean:
     - They may have trouble controlling their urine or their bowels.
     - They may have trouble having and keeping an erection.
   - Only you know what will make you feel that you have made the best decision.

4. Your partner’s concerns
   - Partners often have concerns of their own. As you’re reviewing information important to your decision, the doctor can help your partner get his/her questions answered as well.

5. 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 partner
   - You may want to talk this over with your spouse/partner or other people you trust. There are many facts to understand and options to balance. Talking it over with them may make your load lighter.
   - You may prefer to make your own decision.
   - You may want to talk to other men who have had prostate cancer. (See page 29 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 (also called a urologist) [ur ALL o jist], a radiation oncologist, a medical oncologist, a urologic oncologist, or your primary care doctor 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: Observation - Watchful Waiting and Active Surveillance

What happens

- With Watchful Waiting and Active Surveillance you do not start surgery or radiation right away.

- 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.

- Active Surveillance involves regular PSA blood tests, prostate exams, imaging studies, and prostate biopsies with the plan to do active treatment at a later time if needed. Active Surveillance is a relatively new way to do observation. How many tests are done and how frequently varies from office to office. It is not yet known whether active surveillance is better than immediate active treatment.

- Watchful Waiting involves less frequent PSA blood tests, prostate exams and prostate biopsies than active surveillance. These are only done if there is concern that the cancer is growing too fast.

How observation can help

- Some doctors think it’s a good idea to do observation with active surveillance or watchful waiting:

  - **Active Surveillance** may be right for you if you have a small cancer confined to the prostate gland and it does not appear to be spreading or growing fast. If it does grow then you can still be treated to cure the cancer.

  - **Watchful Waiting** may be right for you if 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 other treatments later.

- It is lower in cost (time and money). Active surveillance is more costly than watchful waiting.
When the doctor told me that I could choose observation, 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 observation 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.

“When the doctor told me that I could choose observation, 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.”
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.

• A surgeon can perform surgery in several ways. One way to remove the prostate is to put a lighted tube (called a laparoscope) through the abdomen and even use robotics to help with surgery. With robotic assisted surgery the surgeon uses a device that replaces his/her hands with robotic hands, placed into the abdomen next to the lighted tube. If he or she does not use robotic help, the surgeon can get to the prostate through the lower abdomen or from in between the legs, near the scrotum. As long as your surgeon is experienced the way the surgery is done usually doesn’t matter.

• 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 about a week to help you heal.

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

The good news was that prostate cancer is not a death sentence. It is not an emergency. Treatment does not have to be started right away. The treatment may completely destroy the cancer.

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

How this treatment may cause problems

1. All of the cancer cells may not have been removed with surgery.
   - Sometimes men may need more treatment, such as radiation, to the area of surgery to give them the best chance of curing their cancer.

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, or in the urine.
   - **Problems holding urine (also known as incontinence)** [in KON te nenz]: 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 most cases, 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 pad to protect your clothes, 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.
     - Younger men usually have fewer problems controlling their urine after surgery.
   - **Problems passing urine:** Passage of urine improves for most men because the prostate gland, that can block urine flow, has been removed. For some other men, scars can form inside the tube (the urethra) that carries urine out of the penis. About 5 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 getting 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 40 men out of 100 have long term impotence after surgery.
  - About 30 out of 100 men will return to nearly their original levels of sexual ability.

**The risk of being impotent depends on a few things:**

  - If your erections were good before surgery, then you will probably have fewer problems with erections after surgery.
  - If you have nerve sparing surgery, the chance of impotence is lower.
  - If you are younger, the chance of impotence is lower.

**Your doctor can help you treat the impotence with:**

  - Medicine that helps with erections.
  - Vacuum device.
  - Injections into your penis to cause an erection.
  - A surgical implant that allows you to have an erection when you want one.

Each man (and partner) will need to decide which treatments they are interested in trying when problems arise. However, some men may have already stopped having sex before starting prostate cancer treatment and others may feel that some of these treatments are not worth the effort it takes to try them.

There are specialists who can help men and partners get their sexual relationships back on track after treatment even when the man’s erections are not what they used to be. They are called “sex therapists” and information about where to contact them is on the website of the American Association of Sexuality Educators, Counselors, and Therapists (www.aasect.org).

• **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, many men will feel relieved, but some may also feel sadness especially if they experience side effects. This is a stressful time. If these feelings are difficult for you, there are many ways to get help, including talking with your doctor, counselor, self help books, talking openly to family and friends, and going to a prostate cancer support group.

Websites like [http://www.prostatecancerdecision.org](http://www.prostatecancerdecision.org) also have support materials for men with prostate cancer.
A Treatment Choice: Radiation

What happens
There are 2 types of radiation treatments: external radiation and internal radiation. Your doctor may advise one or the other or both 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 get treatments as an outpatient. You are not hospitalized.
- You go to a hospital or a clinic 5 days a week, for between 7 and 9 weeks.
- Each treatment lasts about 15-30 minutes.
- Men can continue to work while getting radiation treatments.
- There are different techniques of planning and delivering external beam radiation. Names you may hear include:
  - Image Guided Radiation Treatment (IGRT)
  - 3 D Conformal External Beam Radiation
  - Intensity Modulated Radiation Treatment (IMRT)

All are ways to plan radiation treatment delivery that will lead to fewer side effects and better control of the cancer than regular beam radiation.

If you have a prostate cancer that is considered to be more likely to come back after treatment, your doctor may recommend medicines that temporarily decrease your testosterone (a natural male hormone) during your radiation therapy.

- The combination has been shown to improve the chances that your treatment is successful for high risk patients.
- Hormone therapy may last for several months or years. 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, weight gain, loss of muscle, and loss of energy.
2. Internal radiation: Also called brachytherapy (bray-kee-THER-a-pee)

- Radiation seeds are placed into the prostate, or the prostate is radiated from the inside out, using tubes or catheters.
- This is done in the operating room, but you do not check into a hospital. You get treated as an outpatient.
- The radiation destroys cancer cells inside the tumor. But they do not do much damage to the tissue around the prostate. The implant may be left in temporarily or be permanent.
- Doctors sometimes use external beam radiation along with the seeds or implant.

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 observation.
- 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 this treatment 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 (incontinence):**
  You may have just a few weeks of not being able to control your urine.
  - But about 2 to 5 men out of 100 have this as a permanent problem from internal radiation. This means 95 to 98 men out of 100 will not have this urination problem.
  - 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 a prostate or urinary tract infection. You may also have to pass urine more often.
  - For about 90 out of 100 men this does not happen or is only temporary.
  - It will be a permanent problem for about 10 men out of 100 receiving external beam radiation. It may be a problem for more men who have internal 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 35 men out of 100 have a moderate to big problem with erections. This means that 65 men out of 100 do not think their sexual function is a bother after treatment.
  Even if you are able to have an erection after radiation, you may have a decrease in the amount of fluid (semen) that comes out during ejaculation.

• **Your doctor can help you treat the impotence with:**
  - Medicine that helps with erections.
  - Vacuum device.
  - Injections into your penis.
  - A surgical implant that allows you to have an erection when you want one.

After radiation, many men will feel relieved, but some may also feel sadness especially if they experience side effects. This is a stressful time. If these feelings are difficult for you, there are many ways to get help, including talking with your doctor, counselor, reading books, talking openly to family and friends, and going to a prostate cancer support group. Websites like [http://www.prostatecancerdecision.org](http://www.prostatecancerdecision.org) also have support materials for men with prostate cancer.

**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 19)
- If radiation does not cure your cancer, surgery may be more difficult because of scarring around the prostate from radiation.

**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.
# 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.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| **Watchful Waiting**              | • It is low in cost (time and money)  
• No side effects or complications from the treatment itself  
• May never need active treatment | • Prostate cancer may spread and become incurable  
• Prostate cancer may get bigger and cause symptoms  
• May lead to more cancer deaths than surgery  
• Involves living with uncertainty |
| **Active Surveillance**           | • You are being closely followed by your doctor  
• No side effects from surgery or radiation unless you decide to change to active treatment  
• May never need active treatment  
• You can focus on other serious illnesses that are more likely to harm your health | • Prostate cancer may spread and become incurable  
• Cancer may get bigger and cause symptoms  
• Involves living with uncertainty  
• Multiple prostate biopsies, PSA tests, prostate exams and office visits may be a lot to deal with  
• Too early to tell whether it may lead to fewer deaths than watchful waiting |
| **Surgery**                      | • May remove all the prostate cancer  
• Gives best idea on how big the cancer is  
• May lead to fewer cancer deaths than observation  
• May help relieve some urinary symptoms | • The cancer may not be completely removed  
• May have problems during surgery  
• You must be in a hospital  
• May have problems having erections  
• May have problems holding urine  
• May have limited activity for several weeks  
• Rare deaths as a result of surgery |
| **External “beam” radiation**    | • 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 slowly | • May not kill all the prostate cancer  
• 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 urinary problems  
• May feel weak and tired during treatment  
• Surgery may be more difficult if radiation is unsuccessful  
• Tiny chance of developing a bladder or rectal cancer many years after treatment |
| **Internal radiation**           | • 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 slowly | • May not kill all the prostate cancer  
• 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 urinary problems  
• May feel weak and tired during treatment  
• Tiny chance of developing a bladder or rectal cancer many years after treatment |
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.

<table>
<thead>
<tr>
<th></th>
<th>Observation</th>
<th>Active Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Watchful Waiting</td>
<td>Active Surveillance</td>
</tr>
<tr>
<td>Problems with erection (Impotence)</td>
<td>10 in 100</td>
<td>**</td>
</tr>
<tr>
<td>Problems holding urine or leaking (Incontinence)</td>
<td>Rare*</td>
<td>**</td>
</tr>
<tr>
<td>Passing urine: Painful or Frequent</td>
<td>Rare*</td>
<td>**</td>
</tr>
<tr>
<td>Loose bowels (Diarrhea)</td>
<td>Rare*</td>
<td>**</td>
</tr>
<tr>
<td>Risk of dying from treatment (Death)</td>
<td>Rare*</td>
<td>**</td>
</tr>
</tbody>
</table>

*Rare means less than 1 in 100.
**Active Surveillance is so new we don’t know the number to put in this table yet.

For the first 3 months after treatment more men have impotence (from surgery), incontinence (from surgery), painful or frequent urination (from radiation), and diarrhea (from radiation) as temporary side effects. This table does not count those temporary side effects. The table only lists the side effects that are present 2 years after treatment.

Studies show that the side effects of surgery appear right away and then stabilize or improve. The side effects of external beam radiation and internal radiation (brachytherapy) tend to happen later and then stabilize or worsen.

The numbers used in the table above come from doctors, patients, and published articles. They are averages for patients of all ages. In general, younger patients may have fewer problems before treatment and fewer side effects after treatment. It is important to consider your current urinary, sexual and bowel function and possible side effects when deciding what treatment is best for you. Your specific risk of side effects may vary depending on your current urinary, sexual and bowel function and other medical history.

There are treatments that can help men who get problems with erections, leaking urine, and frequent urination. Make sure you ask your doctor for help if you have these side effects.
After Your Treatment is Finished

Becoming a Survivor

- After your treatment is finished, you become a cancer survivor. During this time, it is important to get back to enjoyable activities and meaningful relationships.

- It is normal to worry that the cancer may return, but your risk of that is low. Eat healthy foods, exercise, keep your regular checkups, and call your doctor if a new problem occurs.

If you continue to have a problem with urine leaks, sexual function, fatigue, coping, or cancer stress after treatment, you can get help at http://www.prostatecancerdecision.org. When you get to that website, click on the section “Help After Treatment” and you will find 14 guides that suggest ways to help manage these concerns and others.

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)
  - 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.
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 appears 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, active surveillance, surgery, and radiation are all ways to treat your localized prostate cancer. Localized means the cancer just affects the prostate gland. They may work because the cancer is confined to the prostate gland and has not spread.

• In addition to local treatment, your doctor may suggest other treatments such as lowering your natural male hormones, like testosterone, with medication.

What we have not talked about so far: LATER or Advanced 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. Many times a combination of different treatments is needed to cure locally advanced disease.

• 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 that is 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.
- Most men prefer to include their partner when they make the decision with their doctor because they will live and cope with the decision together.
- 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 or active surveillance.
- Men who worry more about living with cancer in their body 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.
Tips for Talking to Your Doctor

1. Let the doctor know when things are confusing to you - show confusion on your face.

2. Ask the doctor to slow down
   a. and explain things differently
   b. so you will be able to explain things to your loved ones
   c. or so you can take notes

3. To help you remember the details of your visit, bring
   a. a tape recorder
   b. a loved one
   c. list of questions
   d. this booklet (write down your questions on page 25)

4. Ask questions.

5. Make your wishes known - let the doctor know your preferences.

6. Ask your doctor about the side effects you care most about.

7. Let the doctor know your other health problems

8. Get a second opinion:
   a. Ask for a referral to see a different kind of specialist (urologic oncologist, radiation oncologist or medical oncologist).

   b. Ask for a follow-up visit with your primary care doctor.
Things You May Want to Ask Your Doctor

Is there anything important for me to know about my cancer before deciding what treatment to receive?

Is there anything about my health (besides my cancer) that could change which treatment is best for me?

What are the next steps in deciding on what treatment I should have?

Based on your experience with patients like me, what are the chances of short and long-term side effects for watchful waiting, active surveillance, surgery, or radiation.

Of the 3 main treatments: observation (watchful waiting and active surveillance), surgery, and radiation, are any of them more likely to keep me alive in the next ____ years? (Write down the number of years that matters most to you.)

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

Who can I talk with about problems holding urine or with having erections after treatment?
Things for You to Think About and Tell Your Doctor

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

__________________________________________________________________________

If you have prostate cancer, your 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 can you do to make sure the doctor knows your goals and worries?

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

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Most</th>
<th>Least</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watchful waiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active surveillance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>External beam radiation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal seed radiation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The treatment you are leaning toward is: (check one)

☐ Watchful waiting
☐ Active surveillance
☐ Surgery
☐ External beam radiation
☐ Internal seed radiation (brachytherapy)
A Review of Medical Words Used in This Booklet

A  active surveillance • Doctors watch the prostate cancer carefully for signs of growth. Surgery or radiation can be started at any time. Uses more tests and procedures than watchful waiting.

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 Score or Gleason Sum.

  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 beam 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 Score • Grade of a prostate cancer resulting from looking at a biopsy sample through a microscope. Also called the Gleason Sum 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 radiation (brachytherapy) • Radiation therapy in which a radiation source, sometimes called seeds or implants, is placed in the prostate.
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.

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.

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

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

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.

prostatitis • Inflamed or infected area of the prostate.

radiation therapy • Treatment using radiation to destroy cancer.

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).

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.

testicles • Male sex glands (balls).

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

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.

watchful waiting • Doctors watch the prostate cancer with a “wait and see” approach. Surgery or radiation can be started at any time. Uses fewer tests and procedures than active surveillance.
A Place for You to Take Notes

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)
• National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (www.cancer.gov)
• Michigan Cancer Consortium (www.prostatecancerdecision.org)
• Urology Care Foundation 1-800-828-7866 (www.urologyhealth.org)

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

Where to get more copies of this booklet
To get more copies of this booklet from the Michigan Cancer Consortium

• Call toll free: 1-800-353-8227 or
• Visit www.prostatecancerdecision.org on the Internet.

Materials are free of charge to Michigan residents and organizations.

All information in this booklet comes from medical research. References are available online from The Michigan Cancer Consortium at www.michigancancer.org.
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This publication is reviewed annually by the Michigan Cancer Consortium’s Prostate Cancer Action Committee with updates made when new scientific evidence has emerged that will assist men to make informed decisions about prostate cancer treatment.

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