

Should I do active surveillance for prostate cancer?

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Prostate Cancer: Should I Choose Active Surveillance?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

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Your Summary

Get the facts

Your options

- Use active surveillance. This means following a schedule of regular checkups and tests.
- Have surgery or radiation instead of using active surveillance.

This decision aid is for men who have low-risk localized prostate cancer and for some men who have medium-risk localized prostate cancer. If you have localized prostate cancer and already know that active surveillance is not an option for you, you may need to decide between surgery or radiation.

Key points to remember

- With active surveillance, you can choose to wait to start treatment, such as surgery or radiation. Some men will never need surgery or radiation. And others will be able to delay having surgery or radiation until tests show that their cancer is growing.
- Surgery or radiation may be used to remove or destroy the cancer right away. But in many cases, the cancer would never have caused you problems. And having these treatments may not cure the cancer.
- Surgery and radiation can cause serious side effects, such as erection, bladder, and bowel problems. And these can have a big impact on your quality of life.
- There is a chance that your prostate cancer may grow during active surveillance. But you will have frequent checkups and tests to watch for any changes. And if the cancer grows, it can still be successfully treated.
- Men with low-risk localized prostate cancer and some men with medium-risk localized prostate cancer have a very low risk of dying from prostate cancer. This is true no matter what approach they choose.

What is localized prostate cancer?

Prostate cancer is the abnormal growth of cells in the prostate. Localized prostate cancer is cancer that hasn't spread outside the prostate.

Localized prostate cancer may be low-risk, medium-risk, or high-risk. Your test results will show your risk level and how likely it is that the cancer will grow. Men with low-risk localized prostate cancer and some men with medium-risk localized prostate cancer have the option of choosing active surveillance.

Unlike many other cancers, prostate cancer is usually slow-growing. For most men, this slow growth means they have time to learn all they can before they decide whether to have treatment or which treatment to have. The main treatment options for men who have localized prostate cancer are active surveillance, surgery, and radiation.

Most men who get prostate cancer don't die from it.

What is active surveillance?

Active surveillance means that you will be watched closely by your doctor. You won't have further treatment unless the cancer starts to grow. If this happens, your doctor may recommend other treatment, such as surgery or radiation.

During active surveillance, your doctor will watch for any changes in the cancer. You will have frequent checkups and tests. These include PSA (prostate-specific antigen) tests, digital rectal exams, and prostate biopsies.

If you choose active surveillance, you can change your mind at any time and have surgery or radiation, even if tests show that your prostate cancer hasn't changed.

A 15-year study followed men on active surveillance. At 5 years, about 24 out of 100 men had other treatment, either because their prostate cancer had changed or because they didn't want to wait to see if their prostate cancer would change. At 10 years, about 36 out of 100 men had other treatment. And at 15 years, about 45 out of 100 men had other treatment.¹

For men with low-risk prostate cancer and for some men with medium-risk prostate cancer, active surveillance may be a better treatment option than surgery or radiation. Whether active surveillance is a good choice for you is something you will want to discuss with your doctor. You and your doctor will want to consider:

- Your age and how long you expect to live.
- Your PSA level.
- Your Gleason score.
- Your prostate biopsy results.
- The side effects you might have from other treatments.
- Your personal feelings and concerns.

If you choose active surveillance, having a doctor who supports your choice is important. So is the support of others who are close to you.

How is active surveillance different from watchful waiting?

Watchful waiting means that you'll still be under the care of your doctor. But the goal of watchful waiting is to only treat symptoms that bother you. (For active surveillance, the goal is to cure the cancer if tests show that the cancer is growing.)

Men who are near the end of their lives and men who have other serious medical conditions and aren't well enough to have surgery or radiation often choose watchful waiting.

What are the benefits of active surveillance?

One of the benefits of active surveillance is that you may be able to avoid treating a cancer that may never be a problem. You also can delay or avoid surgery or radiation and their side effects. The short-term and long-term side effects from having surgery or radiation are serious. They include having trouble getting erections, having urinary problems like not being able to control your bladder, and having bowel problems such as diarrhea or rectal pain.

Another benefit is that you can keep your current quality of life and keep doing the activities you enjoy, at least for a time. Your overall well-being; your physical, mental, and sexual health; and your relationships are all part of your quality of life.

For men with low-risk localized prostate cancer who choose active surveillance, the chance of their cancer spreading is low. One study compared active monitoring (a watch-and-wait program like active surveillance), surgery, and radiation in men who had localized prostate cancer and found that the risk of dying was very low and about the same, no matter what option men chose.²

What are the risks of active surveillance?

There is a chance that your prostate cancer will grow during active surveillance. But if the cancer grows, it can still be successfully treated. Your doctor will recommend treatment, such as surgery or radiation.

If you choose active surveillance, it's very important to follow your doctor's schedule of tests and exams. Regular checkups will increase your chances of finding out right away if your prostate cancer is growing. That way your cancer still can be treated early, when treatments are more successful.

It can be hard to wait to see if your prostate cancer will need treatment. Or you may worry that the cancer might get worse between checkups. Not knowing what might happen may affect your quality of life. Several studies found that 3 to 9 out of 100 men on active surveillance changed their minds and had other treatment because of anxiety (and not due to changes in their prostate cancer).³

Why might your doctor recommend active surveillance?

Your doctor might recommend active surveillance if:

- Your cancer isn't likely to grow because your PSA is low, your Gleason score is low, and the cancer is so small it can only be seen through a microscope.
- Your age and current health make you a good candidate for active surveillance.
- You want to delay or avoid surgery or radiation and their side effects.

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Compare

Compare your options

	Use active surveillance	Have surgery or radiation instead of active surveillance
What is usually involved?	<ul style="list-style-type: none">You will have regular checkups and tests (including prostate biopsies) to watch for any changes in your cancer.If your cancer grows, you will need to have surgery or radiation.	<ul style="list-style-type: none">You will have surgery or radiation to remove or destroy the cancer.After surgery or radiation, you will have regular checkups to make sure the cancer hasn't come back. Or if the cancer wasn't cured by treatment, you'll have checkups to watch for any changes in the cancer.
What are the benefits?	<ul style="list-style-type: none">With active surveillance you have a very low risk of dying from prostate cancer. Even if the cancer grows, most of the time it can be treated early enough that it can still be cured.You can delay or avoid surgery or radiation and its side effects.You can keep your current quality of life and continue your normal activities.You can decide later if you want to have surgery or radiation.	<ul style="list-style-type: none">You treat the cancer right away.With surgery or radiation, you'll still have checkups and tests, but you won't need regular biopsies.
What are the risks and side effects?	<ul style="list-style-type: none">The cancer may grow to the point where it can't be cured during active surveillance.Risks of prostate biopsies include bleeding and infection.You may worry that the cancer might get worse between checkups.	<ul style="list-style-type: none">Treatment may not cure the cancer. Or the cancer could come back.Surgery and radiation have serious side effects, such as erection, bladder, and bowel problems.Risks of major surgery include bleeding, infection, blood clots, problems from anesthesia, and possibly death.Risks of radiation include skin changes (dry, itchy, red skin with peeling or blistering), diarrhea or rectal pain, fatigue, and pain or burning when urinating.

Personal stories about considering active surveillance

These stories are based on information gathered from health professionals and consumers. They may be helpful as you make important health decisions.

When I found out I had prostate cancer, I was scared. My first thought was, "Get it out, now!" But my doctor said that with frequent checkups, I could wait to have surgery, and that I may never even need surgery. After a lot of thought, I decided to wait. I decided that the best way for me to deal with the stress of waiting was to focus on taking better care of myself. So now I'm at the gym 4 times a week, eating a healthier diet, and making sure I get good sleep. I'm also doing more of the things I enjoy, like going fishing with my grandson. And so far, so good. It's been 3 years since I was diagnosed, and I'm doing great.

Alex, 72

If anyone would have told me that I would get prostate cancer someday, let alone have to decide what to do about it, I would have said that it could never happen to me. But it did. My doctor suggested I consider active surveillance. At first I wasn't sure about waiting. But my brother-in-law told me about the problems he's had since his prostate surgery. After talking about it with my family, I decided to wait. I know that I still might need to have surgery or radiation someday, but the longer I can put off the side effects of these treatments, the better.

Darnell, 75

I'm not a patient man. If something needs to be done or taken care of, I don't wait. So when my doctor told me I had prostate cancer, there was no question in my mind that I wanted to treat it right away. For me, waiting to see what might happen wasn't an option—even though my doctor said that it was. I was told about all the possible side effects of surgery, which weren't pleasant and certainly not something I was looking forward to. But I decided that dealing with the side effects would be easier than dealing with the anxiety of knowing that my cancer could grow at any time if I waited. I just knew that I couldn't live with that uncertainty.

Ralph, 64

After I got over the shock of being diagnosed with prostate cancer, I had to decide what to do next. I was really anxious about making the right decision, because the only person I knew who had prostate cancer died from it. And I didn't want that to happen to me. I grappled with the idea of waiting to have surgery. This seemed like a reasonable option since my cancer was small and hadn't spread. But knowing there was a chance that it could get bigger or spread during this time made me nervous. I knew if that were to happen, I would regret not having done something more aggressive from the start. So I decided to have surgery. I know that even with surgery there isn't any guarantee that my cancer won't come back. But at least for now, I'm cancer-free.

Rodney, 67

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What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to use active surveillance

Reasons not to use active surveillance

I want to avoid surgery or radiation for as long as I can.

I want to get rid of my cancer right away.

More important

Equally important

More important

I'm willing to take the risk that the cancer will grow.

I'm worried that if I wait to have surgery or radiation, my cancer will grow.

More important

Equally important

More important

I'm worried that I might not be able to deal with the side effects of surgery or radiation.

I'm willing to deal with the side effects of surgery or radiation.

More important

Equally important

More important

My other important reasons:

My other important reasons:

More important

Equally important

More important

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Where are you leaning now?

Using active surveillance

Having surgery or radiation instead of using active surveillance

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Leaning toward

Undecided

Leaning toward

< Previous

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Current as of: December 17, 2020
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What else do you need to make your decision?

Check the facts

1. Will all men with prostate cancer need surgery or radiation?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

2. During active surveillance, do you need to have regular checkups and tests?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

3. Will having treatment with surgery or radiation right away help me live longer than choosing active surveillance?

- ☐ Yes
- ☐ No
- ☐ I'm not sure.

Decide what's next

1. Do you understand the options available to you?

Yes

No

2. Are you clear about which benefits and side effects matter most to you?

Yes

No

3. Do you have enough support and advice from others to make a choice?

Yes

No

Certainty

1. How sure do you feel right now about your decision?

> > > > > > >

Not sure at all

Somewhat sure

Very sure

2. Check what you need to do before you make this decision.

- ☐ I'm ready to take action.
- ☐ I want to discuss the options with others.
- ☐ I want to learn more about my options.

Use the following space to list questions, concerns, and next steps.

End.

**(section 6 is
simply a
summary)**