



Waitemata
District Health Board

Best Care for Everyone

Monitoring your Prostate Cancer using “Active Surveillance”

What you need to know

This fact booklet is for men who want to know more about monitoring their prostate cancer using Active Surveillance. Your partner, family or friends might also find it helpful.

Active surveillance involves monitoring slow-growing prostate cancer, rather than treating it straight away. This means you can avoid unnecessary treatment and delay the possible side effects of treatment. If there are signs your cancer may be growing, you will be offered treatment which aims to cure it.

The information in this booklet is divided into the following sections:

1. What is active surveillance?
2. Who can go on active surveillance?
3. What are the advantages and disadvantages?
4. What does active surveillance involve?
5. Are there any risks with active surveillance?

Our Specialist Nurses

Our Specialist Nurses can answer your questions, help explain your diagnosis and go through your treatment options with you. They have got time to listen to any concerns you or those close to you have about living with prostate cancer. Everything is confidential.

To get in touch email:

urologycancercoordinator@waitematadhb.govt.nz

1) What is active surveillance?

Active surveillance is a way of monitoring prostate cancer that's contained inside the prostate (localised prostate cancer). You will have regular checks to keep an eye on the cancer including regular Prostate Specific Antigen (PSA) blood tests, prostate biopsies and MRI scans.

The aim is to avoid treatment unless there are signs your cancer may be growing.

It might seem strange not to have treatment, but prostate cancer is often slow-growing and may not cause any problems in your lifetime. In other words, you might never need any treatment.

Many treatments for prostate cancer, like radiotherapy or surgery (radical prostatectomy), can cause side effects. The most common side effects are leaking urine (incontinence), difficulty getting and keeping an erection (erectile dysfunction) and bowel problems. For some men these side effects may be long-term and can have a big impact on their daily lives.

If you decide to go on active surveillance, you won't have any treatment unless your tests show that your cancer may be growing – so you'll avoid or delay these side effects. If there are signs that your cancer may be growing, you will be offered treatment which aims to cure it.

Many men on active surveillance won't need treatment in their lifetime.

2) Who can go on active surveillance?

Your urology doctor will look at the test results used to diagnose your cancer – such as your PSA level, biopsy results, and any scans you have had – to get an overall idea of:

- How far your cancer might have spread (its stage)
- How quickly it may be growing

Your urology doctor will also look at the amount of cancer found in each prostate biopsy core (sample) and the total number of cores from your sample that had cancer in them.

From this information your urology doctor can work out your risk group and decide if active surveillance is an option for you.

Active surveillance is suitable for men with prostate cancer that's contained inside the prostate (localised prostate cancer) and is less likely to spread (very low and low risk). It is generally not recommended for men with cancer that may be more likely to spread (medium risk). If you have more aggressive prostate cancer which is more likely to spread (high risk), active surveillance will not be suitable for you.

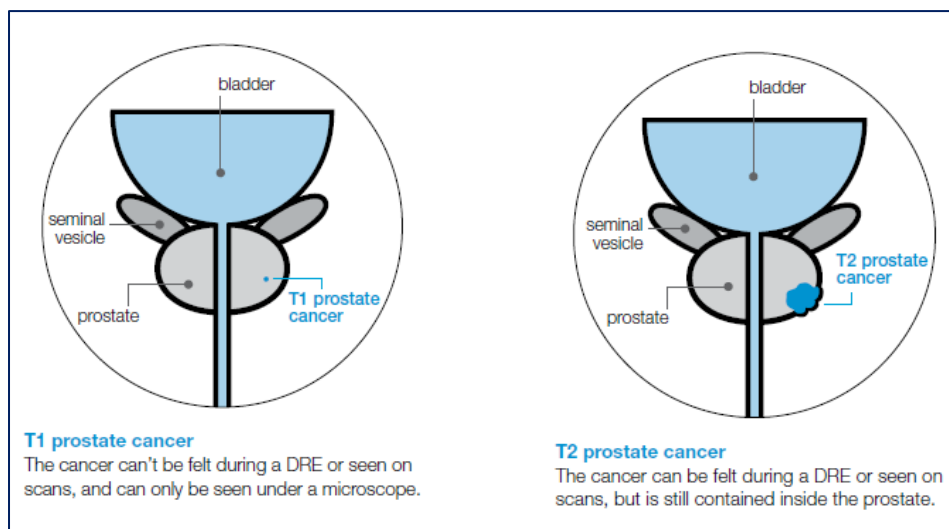
Grading

This score refers to the aggressiveness of the tumour that is the expected speed of growth. There are 2 scoring systems used - a Gleason score or an ISUP grade.

Gleason score	Description	ISUP grade
6 (3 + 3)	All the cancer cells found in the biopsy look likely to grow slowly.	1
7 (3 + 4)	Most of the cancer cells found in the biopsy look likely to grow slowly. There are some cancer cells that look likely to grow at a moderate rate.	2

Staging

This score refers to the amount of disease and the area found in the prostate.



Very low Risk

Your cancer may be described as very low risk if:

- Your PSA level is less than 10 ng/ml, and
- Your Cancer grading score is ISUP 1 (Gleason 6 or less) and
- Two or less of the prostate biopsy cores had cancer in them and
- Less than half of the length of each positive prostate biopsy core had cancer in it
- The stage of your cancer is identified as T1

Low Risk

Your cancer may be described as low risk if:

- Your PSA level is less than 10 ng/ml, and
- Your Cancer grading score is ISUP 1 (Gleason 6 or less) and
- The stage of your cancer is identified as T1 to T2a

Medium (Intermediate) Risk

Your cancer may be described as medium risk if:

- Your PSA level is between 10 and 20 ng/ml, or
 - Your Gleason score is 7, or
- The stage of your cancer is identified as T2b

Prostate Specific Antigen (PSA) Test

The PSA test is a blood test that measures the total amount of prostate specific antigen (PSA) in the blood. PSA is a protein produced by normal cells in the prostate, and also by prostate cancer cells.

You will have had a PSA test to help diagnose your cancer. It's also a very useful test for monitoring prostate cancer.

MRI scan

MRI (magnetic resonance imaging) uses magnets to create a detailed picture of your prostate and the surrounding tissues. You might have an MRI scan when you are diagnosed with prostate cancer to find out whether the cancer has spread outside the prostate.

Other things to think about

When deciding if active surveillance is a suitable option for you, your doctor will also make sure that

- You are fit enough to have treatment such as surgery or radiotherapy
- You know about the advantages and disadvantages of being on active surveillance
- You have discussed other treatment options with your doctor or nurse and you have decided to go on active surveillance

Other treatment options

There are a number of treatments for localised prostate cancer and there may be more than one which is suitable for you. Your doctor or nurse should discuss the advantages and disadvantages of all the different treatment options with you. Other treatment options include:

- **Surgery** to remove the prostate (radical prostatectomy)
- **External beam radiotherapy** (EBRT) which uses X-ray beams to kill the cancer
- **Brachytherapy** – a type of internal radiotherapy. This is not available in our public health system at this time, but it is available in the private sector.

- **Watchful waiting** - a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term, and avoid treatment unless symptoms occur

If you are on active surveillance and your tests show that your cancer might be growing, you will be offered treatment to cure your cancer.

Unsure about your diagnosis and treatment options?

If you have any questions about your diagnosis at any time, ask your urology doctor or nurse. They will explain your test results and talk you through your treatment options. Make sure you have all the information you need.

3) What are the advantages and disadvantages of active surveillance?

What may be an advantage for one person might not be for someone else. If you are offered active surveillance, speak to your urology doctor or nurse – they will be able to help you decide whether it's the right option for you.

There is usually no rush to make a decision so give yourself time to think about whether active surveillance is right for you.

Advantages

- As you won't have treatment while you are on active surveillance, you will avoid the side effects of treatment
- Active surveillance does not interfere with your everyday life as much as treatment might do
- If tests show that your cancer might be growing, there will be treatments available that aim to cure it

Disadvantages

- You might need to have more prostate biopsies which can cause side effects, and which some men find uncomfortable or painful
- There is a chance that your cancer might grow more quickly than expected and become harder to cure
- Your general health could change, which might make some treatments unsuitable for you if you did need them
- Some men may worry about not having treatment and about their cancer growing

4) What does active surveillance involve?

If you are on active surveillance you will have regular tests to monitor your cancer. The tests aim to find any changes that suggest the cancer is growing. If any changes are found, you can have treatment which aims to cure the cancer – such as surgery or radiotherapy.

The tests used vary a little from person to person, hospital to hospital, but you will have:

- A PSA test every three to six months
- A digital rectal examination (DRE) every 12 months
- A prostate biopsy within a year after you were diagnosed, and then every few years
- MRI scan(s) to help with targeting and tumour volume assessment

PSA Test

The PSA test is a useful way of monitoring prostate cancer. Your doctor will check any changes in your PSA level – if it rises, they will look at how much it has risen and how quickly. If your PSA level rises faster than expected, then your doctor might recommend a prostate biopsy or an MRI scan to check if the cancer is growing.

A rise in your PSA level could be a sign that your cancer is growing, but a number of other things can cause it to rise – including age and infection. You should let your doctor know if you are taking any medication or supplements as they might also affect your PSA level.

Digital rectal examination (DRE)

This is where the doctor feels your prostate through the wall of the back passage (rectum). They will wear gloves and put some gel on their finger to make it more comfortable. Some men find it embarrassing but the test will be over quickly.

If your doctor or nurse feels any changes to your prostate, such as any hard or irregular areas, this could suggest the cancer is growing. They might recommend a prostate biopsy or an MRI scan.

MRI scan

You might be offered an MRI scan to help with targeting tumour biopsies and to assess tumour volume. The scan can help your doctor decide if you need another biopsy.

Prostate biopsy

You will have a repeat prostate biopsy within 12 months of the first biopsy you had when you were diagnosed. Then you might have more biopsies every few years depending on your PSA and DRE results.

Will I need treatment?

If the results of the tests show your cancer has grown, you will be offered treatment which aims to cure the cancer – for example, surgery or radiotherapy.

Most men on active surveillance have treatment because their tests show their cancer has changed. But some men decide they want to have treatment even though there are no signs of any changes. This is often because they are worried their cancer will spread. If you decide you do want treatment, speak to your doctor or nurse about your options.

5) Are there any risks with active surveillance?

Changes to your cancer

If you have active surveillance there is a chance that your cancer could grow. But remember that the tests used to monitor your cancer aim to find any changes early enough to treat it. Men who go on to have treatment after being on active surveillance can still have their cancer treated with surgery, radiotherapy or other treatments which aim to cure the cancer.

Although the tests used in active surveillance are reliable at finding changes in your cancer, there is always a small chance that changes might be missed. This means there is a small chance that the cancer will spread outside your prostate before being picked up, and treatment might not be able to get rid of it.

Sometimes, men who have been diagnosed with low risk prostate cancer actually have a more aggressive cancer, which should be treated. This is because prostate biopsies collect small pieces of tissue from the prostate, so it's possible that some areas of cancer can be missed. Most men have another prostate biopsy within a year of being diagnosed, and then every few years. The aim of these tests is to check how the cancer is behaving.

Research shows active surveillance is a safe way of avoiding unnecessary treatment for men with low risk prostate cancer. Talk to your doctor or nurse about the risk of your cancer growing.

Changes to your health

There is a chance that your general health could change, which would make some treatments unsuitable for you if the cancer did grow.

For example, if you were to get heart problems, you might not be able to have surgery to remove the prostate, as an operation might not be safe for you.

Concerns about active surveillance

Active surveillance isn't for everyone. You might find it difficult not having treatment for your prostate cancer and worry that it will change or spread. Some men on active surveillance decide to have treatment even though there are no signs of any changes in their cancer – because they are worried about it growing.

If at any time you decide that you want treatment, talk to your doctor or nurse about your treatment options. You don't have to stay on active surveillance if you do not want to.

Are there any side effects?

As you won't have treatment while you are on active surveillance, you won't get any of the side effects of treatment.

Prostate biopsies can cause some short term side effects such as infection, and blood in the urine, semen or bowel movements.

About 1 in 50 men (2%) may get a serious infection after a TRUS biopsy. You will have antibiotics before your biopsy to help prevent infection.

You can discuss all the advantages and disadvantages of active surveillance with your doctor or nurse, to help you decide whether it's right for you.

Local Support groups

You can find out information about support groups in your area by contacting the Prostate Cancer Foundation NZ on 0800 4 PROSTATE (0800 477 678) or Email info@prostate.org.nz

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