

# Active surveillance

This fact sheet is for men who would like to know more about an approach to prostate cancer treatment called active surveillance. It is one of several fact sheets that have been written to help you decide which treatment is best for you. It may also be useful for the partners and family of men with prostate cancer. It describes how some men with less aggressive prostate cancer can be monitored, avoiding or delaying the side effects of treatment. Each specialist team will do things slightly differently so use this fact sheet as a general guide and ask your specialist team for more details about the treatment you will have. If you have any questions about active surveillance, you can speak to your specialist team or call our confidential Helpline on 0800 074 8383.

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## What is active surveillance?

Active surveillance is a way of monitoring prostate cancer which aims to avoid or delay unnecessary treatment in men with less aggressive cancers. Many prostate cancers are detected at an early stage by a prostate specific antigen (PSA) test. Prostate cancer can be slow growing and, for many men, the disease may never progress or cause any symptoms. In other words, many men with prostate cancer will never need any treatment.

Treatments for prostate cancer can cause side effects which can affect your quality of life. By monitoring the cancer through active surveillance, you can avoid or delay these side effects. The most common side effects include problems getting and keeping an erection (erectile dysfunction) and problems controlling or passing urine (incontinence). For more information about the side effects of each treatment, read our other **Tool Kit** fact sheets.

Active surveillance involves monitoring your prostate cancer with regular tests, rather than treating it straight away. The tests aim to find any changes that suggest that the cancer may grow and cause symptoms. Treatment can then be offered at an early stage, with the aim of getting rid of the cancer completely.

Monitoring will vary between hospitals, but will typically involve:

- PSA testing every three months for two years, then every six months from then on.
- Digital rectal examinations (DRE) every three to six months for two years, then every year.
- Repeat prostate biopsies every few years, depending on your treatment centre.

If you had less than 10 samples of prostate tissue (cores) taken when you were diagnosed, you may need to have another biopsy. Biopsies can cause some bleeding, and there is a small risk of getting an infection. You should discuss these problems with your specialist team if you are concerned.

You can find out more about PSA testing, digital rectal examinations and biopsies by reading our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

If there are any signs that the cancer is changing, your specialist will discuss with you whether you should have treatment and what the treatment options are. You may also decide at any time that you would feel happier starting treatment.

## Is active surveillance the same as watchful waiting?

No, it is very different. Watchful waiting aims to avoid treatment unless symptoms develop. Then, when treatment starts, it is aimed at controlling the cancer rather than getting rid of it. Watchful waiting can be suitable for men with other health problems or who may be less able to cope with treatment.

If men on watchful waiting get symptoms, such as problems passing urine or bone pain, their cancer can be controlled with hormone therapy.

Watchful waiting involves less monitoring than active surveillance and is often carried out by your GP rather than your specialist team at the hospital. If watchful waiting has been recommended as an option for you but you would prefer a different treatment, you should discuss this with your specialist.

## What is active monitoring?

Some people use the term active monitoring to describe both watchful waiting and active surveillance. It can mean different things to different people so it is important that you talk to your specialist team to find out exactly what type of monitoring you are being offered.

## Who can have active surveillance?

Active surveillance is suitable for men with low risk early stage prostate cancer that is contained within the prostate gland (localised prostate cancer). It may also be suitable for some men with medium risk cancer, and your specialist will discuss whether it is an option for you. High risk cancers are not suitable for active surveillance.

Men with low risk cancer will have a PSA level of less than 10 ng/ml and a Gleason score of six or less. The biopsy result should show that there was cancer in less than half of the samples taken. Medium risk cancer is a PSA level of 10-20 ng/ml or a Gleason score of 7 (3+4).

There is more information about PSA levels and Gleason scores in our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

Your specialist team may also consider the amount of cancer cells found in each sample taken during the biopsy. Active surveillance may be suitable if you have a small amount of cancer cells in the samples.

There are some other tests that you may have to help decide whether active surveillance is suitable for you, but these are much less common and you may not be offered them. These are:

- Measuring your PSA density
- A free and total PSA test.

### PSA density

Your specialist team may measure your 'PSA density'. This measures your PSA level in relation to the size of your prostate gland. Men with larger prostate glands have higher PSA levels. You will usually need to have a PSA density of less than 0.15 ng/ml/ml to have active surveillance. You can work out your PSA density by dividing your PSA level by the volume of your prostate gland.

#### For example,

- Prostate volume = 50ml
- PSA level = 7 ng/ml
- PSA density = 7 divided by 50 = 0.14

In this example, the PSA density is less than 0.15, which means that active surveillance may be a suitable option. Your specialist team can tell you the volume of your prostate gland and can help to explain more about PSA density.

### Free and total PSA test

In some cases you may be offered a free and total PSA test to help show how aggressive the prostate cancer is. This measures the ratio between two different types of PSA found in the blood (free and total). There is evidence that suggests that men with less aggressive cancer will have a higher amount of free PSA. Active surveillance may be suitable for men with more than 20 per cent free PSA. This test is not available in every treatment centre. You can ask your specialist team whether it is available in your area.

### Other treatment options

Your specialist team should discuss the advantages and disadvantages of all your treatment options with you. Other treatment options for cancer that has not spread outside the prostate gland (localised cancer) may include:

- Radical prostatectomy
- External beam radiotherapy
- Brachytherapy
- Watchful waiting

You may also be offered high intensity focused ultrasound (HIFU) or cryotherapy as part of a clinical trial or through private healthcare. These treatments are not used very often in the NHS as a first treatment because we do not know enough about their long term benefits and risks.

For more information on all of the treatments listed above, please read our range of **Tool Kit** fact sheets or call our confidential Helpline on 0800 074 8383.

## What are the advantages and disadvantages of active surveillance?

### Advantages

- As there is no physical treatment involved, there are none of the physical side effects associated with other treatments.

- It does not interfere with your everyday life as much as treatment.

### Disadvantages

- Some men may become anxious or worry about their cancer changing.
- You may need to have more prostate biopsies.
- There is a small chance that the cancer may grow more quickly than expected and become more difficult to treat.

What might be an advantage for one person may not be for someone else. Please talk to your specialist team about your own situation.

#### **A personal experience**

*'Active surveillance gave me time to come to terms with the fact that I had prostate cancer, which helped when the time came for my radical prostatectomy.'*

## What happens if my PSA level rises or my biopsy or DRE results change?

### PSA level

A rise in the level of PSA in your blood may be a sign that your cancer is growing. The rate at which your PSA level changes (PSA velocity) and the speed at which it doubles (PSA doubling time) can give you and your specialist team an idea of the rate at which the cancer is likely to grow. Your specialist team will look at how much your PSA level has risen and over what time period. Your PSA level can be affected by other factors, such as age, urinary infection or some medicines, but if it rises at a significant rate then treatment may be recommended.

### Biopsy results

If your repeat biopsy results show a larger amount of cancer or a higher Gleason score than your previous results, you may be offered treatment.

### Digital rectal examination (DRE)

If the doctor or nurse feels any changes during the digital rectal examination then treatment may be recommended.



## Questions to ask your specialist team

How often will I have my PSA level checked?

Who will check my PSA level and give me the results?

How often will I see my specialist team?

How often will I have a digital rectal examination?

Will I need repeat prostate biopsies and how often?

How quickly would my PSA level have to rise for you to recommend treatment?

What treatments could I have if my cancer grows?





The Prostate Cancer Charity makes every effort to make sure that its services provide up-to-date, unbiased and accurate facts about prostate cancer. We hope that these will add to the medical advice you have had and will help you to make any decisions you may face. Please contact your doctor if you are worried about any medical issues.

The Prostate Cancer Charity funds research into the causes of, and treatments for, prostate cancer. We also provide support and information to anyone concerned about prostate cancer. We rely on charitable donations to continue this work. If you would like to make a donation, please call us on 020 8222 7666.

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References to sources of information used in the production of this fact sheet are available on our website

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