

Active surveillance

This fact sheet is for men who would like to know more about how localised prostate cancer can be monitored to find those cancers that will benefit most from treatment. It is one of several fact sheets that have been written to help you decide which treatment is best for you. It describes how some men with low risk prostate cancer can be monitored, avoiding or delaying the side effects of treatment. If you have any questions about active surveillance, you can speak to your specialist team or call our confidential Helpline.

What is active surveillance?

Many prostate cancers are diagnosed at an early stage by Prostate Specific Antigen (PSA) testing. Prostate cancer is often very slow growing and for many men with prostate cancer, 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 lifestyle. By monitoring the cancer with active surveillance, you can avoid or delay the side effects of treatment. The most common side effects of treatments for localised prostate cancer include problems getting and keeping an erection and urinary incontinence. Our other Tool Kit fact sheets give more information about the side effects of treatments.

Not all prostate cancers need treatment. Active surveillance aims to find those cancers that are likely to grow and cause symptoms if they are not treated. These cancers can then be treated at an early stage.

Active surveillance is only suitable for men with low to medium risk prostate cancer. High risk cancers usually need to be treated straight away. If there is a risk that your cancer may cause symptoms if it is left alone, then you will be offered treatment.

Active surveillance involves monitoring your prostate cancer to begin with, rather than treating it straight away. Typically, monitoring involves:

- PSA testing - every three months for two years, then every six months from then on,
- regular Digital Rectal Examinations (DRE),
- repeat prostate biopsies every two to three years.

If you choose active surveillance, you will need to have a biopsy which takes at least ten samples (cores) of prostate tissue. If, when you were diagnosed, your biopsy did not take this many samples, you may need to have another biopsy straight away.

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

The monitoring programme, including the interval between biopsies, may vary between hospitals. Continued observation of the cancer is important to identify any change. Any sign that your cancer is growing should be picked up at an early stage and your specialist will discuss with you whether you should have treatment for it and what treatment options are available.

You may decide to have treatment if your biopsy results show that your Gleason score has increased or if your PSA level is rising at a fast rate. Or you may decide at any time that you would feel happier starting treatment. There is more information about Gleason scores and PSA levels in our fact sheet on **How prostate cancer is diagnosed.**

Who can have active surveillance?

You may be suitable for active surveillance if you have localised prostate cancer that may never need treatment. Usually your PSA level should be less than ten and your Gleason score should be six or less.

However, depending on your individual situation and your personal preferences, your specialist team may offer you active surveillance if your cancer has slightly higher risk features. Your PSA level may be up to 15 and your Gleason score may be up to 7.

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, if:

- the volume of your prostate gland is 50cc and
- your PSA level is 7 ng/ml, then
- your PSA density will be 7 divided by 50, which is 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 what PSA density means.

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 HIFU (High Intensity Focused Ultrasound) 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 other Tool Kit

fact sheets or call our confidential Helpline on 0800 074 8383.

Is active surveillance the same as watchful waiting?

No, it is very different. Watchful waiting aims to avoid treatment unless symptoms develop. If men on watchful waiting get symptoms, such as problems passing urine or bone pain, they can be controlled with hormone therapy. Watchful waiting involves less monitoring than active surveillance and is usually carried out by your GP rather than your specialist team at the hospital. Watchful waiting can be suitable for older men, or those with other health problems that make them unsuitable for other treatments.

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.

What are the advantages and disadvantages of active surveillance?

These will vary from person to person. Please talk to your doctor or specialist nurse about your individual case.

Advantages

- As there is no physical treatment involved, there are no physical side effects.
- 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 will need to have more prostate biopsies.

Why do I need a repeat prostate biopsy?

You will need to have biopsies every two to three years to check that your cancer has not progressed. The biopsy results will tell you the Gleason score of your cancer. Your specialist team will use this Gleason score

together with your PSA test result to estimate the risk of your prostate cancer growing.

What happens if my PSA rises or my biopsy results change?

PSA

The rate at which your PSA level changes 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 the PSA has risen and over what time period. Your PSA level can be affected by other factors, such as infection or some medicines, so your specialist will be looking for a series of PSA rises rather than a one-off change. If your PSA rises at a significant rate then you will be offered treatment.

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.

Are there any side effects?

As active surveillance involves no treatment there are no physical side effects. However some men worry about their cancer changing or spreading and this can lead to anxiety or depression. If this happens you should discuss this with your specialist team. You can also call our confidential Helpline on 0800 074 8383. So far, studies have shown no difference between anxiety levels of men who choose active surveillance and those who decide to have treatment straight away.

What if I change my mind?

You can still have treatment at any time you choose. Your specialist team will discuss your treatment options with you. For more information on treatments, you can read our other Tool Kit fact sheets or call our confidential Helpline on 0800 074 8383.

Questions to ask your specialist team

- Do I need to have treatment straight away?
- How often will I have my PSA checked?
- Who will check my PSA 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 might the repeat biopsy results show that I need treatment?
- How quickly would my PSA level have to rise for you to recommend treatment?

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 already been given and will help you to make any decisions you may face. Please do continue to talk to 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.

The Prostate Cancer Charity
First floor, Cambridge House,
100 Cambridge Grove, London W6 0LE

- **Email:** info@prostate-cancer.org.uk
- **Website:** www.prostate-cancer.org.uk
- **Telephone:** 020 8222 7622
- **Fax:** 020 8222 7639

 **Confidential Helpline**
0800 074 8383

Mon-Fri 10am-4pm, Wed 7pm-9pm

Calls are free of charge from UK landlines.
Mobile phone charges may vary.

- **Email:** helpline@prostate-cancer.org.uk

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A charity registered in England and Wales (1005541) and
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More information

The Prostate Cancer Charity

This fact sheet is part of the Tool Kit. Call our Helpline on 0800 074 8383 or visit our website at www.prostate-cancer.org.uk for more Tool Kit fact sheets, including a Glossary which explains some of the words and phrases used in this sheet.

Cancerbackup

www.cancerbackup.org.uk

3 Bath Place, Rivington Street, London EC2A 3JR

Freephone 0808 800 1234

Mon-Fri 9am-8pm

For information on coping with cancer and treatment.

Macmillan Cancer Support

www.macmillan.org.uk

89 Albert Embankment, London SE1 7UQ

Macmillan cancerline: 0808 808 2020

Mon-Fri 9am-9pm

Practical, emotional and financial support for people with cancer, family and friends.

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

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