

Active surveillance



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This fact sheet is for men who would like to know more about an approach to prostate cancer treatment called active surveillance. Partners and family of men with prostate cancer may also find this information useful.

It describes how some men with less aggressive prostate cancer can be monitored rather than being treated straight away, avoiding or delaying the side effects of treatment.

Each hospital will do things slightly differently so use this fact sheet as a general guide and ask your doctor or nurse for more details about the treatment you will have. If you have any questions about active surveillance, you can speak to your doctor or nurse or call our Specialist Nurses on our confidential helpline.

What is active surveillance?

Active surveillance is a way of monitoring prostate cancer which aims to avoid unnecessary treatment in men with less aggressive cancer. Prostate cancer can often be slow growing and, for many men, it may never progress or cause any symptoms. In other words, many men with prostate cancer may never need any treatment.

Treatments for prostate cancer may cause side effects which can affect your quality of life. By monitoring the cancer with regular tests you can avoid or delay these side effects. The most common side effects of treatment are problems getting and keeping an erection (erectile dysfunction) and leaking urine (incontinence). For more information about the side effects of each treatment, read our **Tool Kit** treatment 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 the cancer is growing. If any important changes are found then treatment can be offered at an early stage, with the aim of getting rid of the cancer completely.

Monitoring varies from hospital to hospital but if you choose active surveillance, you will have the tests listed below.

- **Prostate specific antigen (PSA) tests**

You will have these every three to six months. They measure the amount of PSA in your blood. PSA is a protein produced by cells in the prostate.

- **Digital rectal examinations (DRE)**

You will have these every three to six months for two years, then every year. A DRE is where a doctor or nurse feels your prostate gland through the wall of your back passage (rectum).

- **Prostate biopsies**

You will normally have these every few years, depending on your treatment centre. A biopsy involves taking small pieces of prostate tissue to look at more closely under a microscope for signs of prostate cancer. It will be like the biopsy you had when your cancer was first found. You may hear this called a trans-rectal ultrasound (TRUS) guided prostate needle biopsy.

Some men may have a template or saturation biopsy which involves taking more tissue samples than a TRUS biopsy – usually about 32 samples from different areas of the prostate gland. This procedure is normally done under general anaesthetic.

There is a greater chance of finding prostate cancer cells using a template or saturation biopsy because more of the prostate is looked at. Talk to your doctor about the advantages and disadvantages and possible side effects of these types of biopsy.

In some centres you may be offered a type of MRI scan called a diffusion scan to look for any abnormal looking areas to target during the biopsy. Clinical trials are looking at how useful these scans are at detecting and monitoring prostate cancer.



You can find out more about all of these tests by reading our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

If tests show signs that the cancer is changing, your doctor or nurse will discuss with you whether you should have treatment and what the treatment options are. You may also decide

What is the difference between active surveillance and watchful waiting?

Watchful waiting and active surveillance are both ways of monitoring prostate cancer and avoiding immediate treatment. However, there are some differences, including:

- who may be suitable for each approach
- what kind of tests you will have and how often you will have them.

Active surveillance usually involves more regular hospital tests, including prostate biopsies. The aim is to treat the cancer promptly if it shows signs of changing and to try to get rid of it completely. Active surveillance is suitable for men with cancer that is contained within the prostate gland (localised prostate cancer), who are fit enough to have treatment such as surgery or radiotherapy.

Watchful waiting usually involves check-ups at the GP surgery rather than at the hospital. Check-ups usually happen less often than with active surveillance. The aim is to treat the cancer if it starts causing problems or symptoms. Treatment aims to control the cancer rather than getting rid of it completely. Read our Tool Kit fact sheet, **Watchful waiting** for more information.



Other terms you might hear

Some people use other terms such as active monitoring and 'wait and see' to describe both watchful waiting and active surveillance. The terms can mean different things to different people so it is important that you talk to your doctor or nurse to find out exactly what type of monitoring you are being offered.

at any time that you would feel happier starting treatment. Some men find it difficult to live with prostate cancer and worry that it may change or spread. Some men on active surveillance may choose to have treatment even though there is no change in their cancer because they are worried about it.

You may find that it helps to talk to family or friends about how you are feeling. You could also speak to your doctor or nurse or call our Specialist Nurses on our confidential helpline. Find out more about ways to get support on page 5.



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 intermediate risk cancer, and your doctor or nurse will discuss whether it is an option for you. If you have high risk localised prostate cancer, you will probably not be advised to have active surveillance.

To work out your risk group, your doctor will look at:

- your PSA level
- your Gleason score, which shows how aggressive your cancer is likely to be, and
- the stage of your cancer, which shows how far your cancer has spread.

Low risk

Your cancer may be described as low risk if:

- your PSA level is 10ng/ml or less, and
- your Gleason score is 6 or less, and
- the stage of your cancer is T1 to T2a.

Intermediate risk

Your cancer may be described as intermediate 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 T2b or T2c.

You can read more about risk in our Tool Kit fact sheet, **Localised prostate cancer**.



Your doctor or nurse may also consider the amount of cancer cells found in each sample taken during the biopsy. Active surveillance may be suitable for you if you have cancer in less than half of the samples taken, with only a small amount of cancer in each sample.

Other tests

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. They are described below.

PSA density

Your doctor or nurse may measure your PSA density. This measures your PSA level in relation to the size of your prostate gland. If you have a lower PSA density, active surveillance may be a suitable option. Your doctor will work out your PSA density by dividing your PSA level by the volume of your prostate gland. Your doctor or nurse 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 to suggest that men with less aggressive cancer will have a higher amount of free PSA. This test is not available in every treatment centre. You can ask your doctor or nurse whether it is available in your area.

Other treatment options

Your doctor or nurse 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:

- surgery (radical prostatectomy)
- external beam radiotherapy (EBRT)
- brachytherapy (a type of radiotherapy)
- watchful waiting.

You may also be offered high intensity focused ultrasound (HIFU) or cryotherapy. They are not widely available in the UK and researchers are studying better ways of carrying out these treatments. They may be available in specialist centres or as part of a clinical trial.

 For more information on all of the treatments listed above, please read our range of **Tool Kit** fact sheets or call our Specialist Nurses on our confidential helpline.

Unsure about your diagnosis and treatment options?

If you have any questions about your diagnosis ask your doctor or nurse. They will be happy to explain your test results and talk with you about your treatment options. It is important you feel you have enough time and all the information you need before making a decision about treatment. We have more information about diagnosis and treatment in our **Tool Kit**. You can also speak to our Specialist Nurses on our confidential helpline.

What are the advantages and disadvantages of active surveillance?

Advantages

- As there is no treatment involved, there are none of the physical side effects.
- It does not interfere with your everyday life as much as treatment.

Disadvantages

- You may need to have more prostate biopsies which can cause short term side effects, and which some men find uncomfortable.
- There is a small chance that the cancer may grow more quickly than expected and become more difficult to treat.
- Some men may become anxious or worry about their cancer changing.

What might be an advantage for one person may not be for someone else. Talk to your doctor or nurse about your own situation.

What happens if tests show my cancer may be growing?

PSA level

A rise in the level of PSA in your blood may be a sign that your cancer is growing. Your doctor will look at how much your PSA level has risen and over what time period. This may involve looking at the rate at which your PSA level changes (PSA velocity) and the speed at which it will double (PSA doubling time).

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 your doctor may discuss further biopsies and starting treatment with you.

Digital rectal examination (DRE)

If the doctor or nurse feels any changes to your prostate, such as any hard or irregular areas or changes in size then they may recommend that you start treatment.

Biopsy results

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

MRI results

If you had an MRI and your repeat MRI scan shows the cancer has grown larger, you may be offered treatment.

Research studies have shown that between 14 to 41 per cent of men go on to have treatment during active surveillance. Most men will have treatment because their tests show that their cancer has changed. But some men may decide that they want to have treatment, even when there are no signs of any changes, mostly because they are worried that their cancer will spread.

Are there any risks with active surveillance?

Changes to your cancer

If you have active surveillance, there is a chance that your cancer might grow, but remember that the tests used to monitor your cancer aim to find any changes early enough to treat it successfully.

Studies have found that men who go on to have treatment after a period of active surveillance can still have their cancer treated effectively with surgery or radiotherapy or other treatments.

Although the tests used in active surveillance are reliable at finding changes in the cancer, there is always a small chance that changes may not be picked up. Sometimes, men who have been diagnosed with low risk prostate cancer may actually have a more aggressive cancer which would benefit from treatment. This is because the prostate biopsy may miss the cancer if it is in an area of the prostate where a sample was not taken. There is also a small chance that the cancer may spread outside the prostate or to other parts of the body before being picked up, and treatment will no longer be able to get rid of it.

You can talk to your doctor or nurse about your own risk of your cancer growing.

Changes to your health

There is also a risk that your general health may change, which would make some treatments unsuitable for you if the cancer did grow. For example, if you were to develop heart problems, you may be advised not to have surgery to remove the prostate, as an operation could be risky for you. You can find out more about staying healthy by reading our fact sheet,



Diet, exercise and prostate cancer.

It is important that you discuss all the advantages and disadvantages with your doctor or nurse, to help you decide whether active surveillance is right for you.

Are there any side effects?

As active surveillance involves no treatment there are no physical side effects. But you may need to have prostate biopsies every few years.

Having a biopsy may cause some short term side effects such as blood in your urine, faeces or semen. About 1 in 50 men (two per cent) are at risk of developing a serious infection after biopsy. You will have antibiotics before your biopsy to help prevent infection.

What if I change my mind?

If you decide that you would prefer to start treatment, you can do so at any point. You should speak to your doctor or nurse about which treatment option is best for you. Depending on when you last had a biopsy, you may need to have tests to see what stage your cancer is at.



For more information on treatments, you can read our other **Tool Kit** fact sheets or call our



Specialist Nurses on our confidential helpline.

Where can I get support?

As well as getting medical help to treat your cancer, you may find that it helps to talk to family or friends about how you are feeling. Sharing concerns can make any decisions about your treatment easier to deal with. You could also speak to your doctor or nurse, or call our Specialist Nurses on our confidential helpline.



Partners and family also often worry about their loved one, and may find it helpful to talk to your doctor or nurse.

Some people find that it helps to talk to other men who have been on active surveillance. There are prostate cancer support groups throughout the country. You can ask your nurse for details, or you can find a list of support groups on our website at **prostatecanceruk.org**



You may find it helpful to speak to someone with experience of prostate cancer. Our support volunteers are all personally affected by prostate cancer and trained to listen and offer support over the telephone. Call our Specialist Nurses on our confidential helpline for more information.

If you have access to the internet, you can sign up to our online community, where you can share your views and experiences with others affected by prostate cancer. Our website address is **prostatecanceruk.org**

If you would rather speak to a professional counsellor, you can ask your GP if there is one available on the NHS or you can get a list of private counsellors from The British Association for Counselling and Psychotherapy (contact details are at the end of this fact sheet).

Questions to ask your doctor or nurse



You may find it helpful to keep a note of any questions you have to take to your next appointment.

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 doctor or nurse?

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 are the risks and benefits of active surveillance for me?

What treatments could I have if my cancer grows?

More information

British Association for Counselling and Psychotherapy (BACP)

www.itsgoodtotalk.org.uk

Telephone: 01455 883300

BACP will help you find qualified counsellors. They are happy to discuss any queries or concerns you have about choosing a counsellor or the counselling process.

CancerHelp UK

<http://cancerhelp.cancerresearchuk.org>

Freephone: 0808 800 4040 (Mon-Fri 9am-5pm)

Part of Cancer Research UK, Cancer Help provides information about all types of cancer and a database of cancer clinical trials.

Healthtalkonline

www.healthtalkonline.org

Watch, listen to, or read personal experiences of men with prostate cancer and other medical conditions.

Macmillan Cancer Support

www.macmillan.org.uk

Freephone: 0808 808 0000 (Mon-Fri 9am-8pm)

Provides practical, financial and emotional support for people with cancer, their family and friends.

About us

Prostate Cancer UK fights to help more men survive prostate cancer and enjoy a better life.

This fact sheet is part of the Tool Kit. You can order more Tool Kit fact sheets, including an



A-Z of medical words, which explains some of the words and phrases used in this fact sheet.

All of our publications are available to download and order from the website. You can also order printed copies by calling **0800 074 8383** or emailing literature@prostatecanceruk.org

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate cancer. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this fact sheet are available at prostatecanceruk.org

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Tell us what you think

If you have any comments about our publications, you can email:

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Speak to our Specialist Nurses

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prostatecanceruk.org

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Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis. To help us continue providing free information, you could make a donation of any amount. Please call us on **020 8222 7666**, visit **prostatecanceruk.org/donations** or text **PROSTATE** to **70004****

There are many other ways to support us. For more details please visit:
prostatecanceruk.org/get-involved

**You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit prostatecanceruk.org/terms



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The helpline is open Mon - Fri 10am - 4pm, Wed 7pm - 9pm

*Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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