

# Active surveillance



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This fact sheet is for men who want to know more about 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.

There is another way of monitoring your cancer called watchful waiting which isn't described here – read about this in our  Tool Kit fact sheet, Watchful waiting.

Each hospital will do things differently, so use this fact sheet as a general guide and ask your doctor or nurse for more details about what to expect. You can also speak  to our Specialist Nurses, in confidence, on 0800 074 8383.

## 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 tests to keep an eye on the cancer. 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 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.

### What's the difference between active surveillance and watchful waiting?

Active surveillance is often confused with watchful waiting – this is another way of monitoring prostate cancer. The aim of both is to avoid having unnecessary treatment. But there are key differences between them, so check with your doctor which one you're being offered.

#### Active surveillance

- If you need treatment, it will aim to cure the cancer.
- It is suitable for some men with cancer that is contained in the prostate (localised cancer).
- It usually involves more regular hospital tests, such as prostate biopsies and MRI scans.

#### Watchful waiting

- If you need treatment, it will aim to control the cancer rather than cure it.
- It's generally suitable for men with other health problems who may be less able to cope with treatments such as surgery or radiotherapy, or whose cancer may never cause problems during their lifetime.
- It usually involves fewer tests than active surveillance. These check-ups usually take place at the GP surgery rather than at the hospital.

#### Other terms you might hear

Some people use other terms such as 'active monitoring' and 'wait and see' to describe both active surveillance and watchful waiting. These terms can mean different things to different people, so ask your doctor or nurse to explain exactly what they mean.

### Who can go on active surveillance?

Active surveillance is suitable for men with prostate cancer that's contained inside the prostate (localised prostate cancer) and is less likely to spread (low risk). In the UK, around two out of five men (40 per cent) with low risk localised prostate cancer are on active surveillance.

It's also sometimes suitable for men with cancer that may be more likely to spread (medium risk), who want to avoid or delay treatment. Your doctor or nurse will discuss whether it's an option for you. If you have more aggressive prostate cancer which is more likely to spread (high risk), active surveillance won't be suitable for you.

### Working out how likely your cancer is to spread

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

- how far your cancer has spread (its stage)
- how quickly it may be growing.

They can then work out your risk group and decide if active surveillance is an option for you.

#### Low risk

Your cancer may be described as low risk if:

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

#### Medium 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 T2b.

You can read more about what your test results mean and working out your risk group in our



Tool Kit fact sheet, **Localised prostate cancer**.

Your doctor will also look at the amount of cancer found in each sample taken during your prostate biopsy. Active surveillance may be suitable for you if you have cancer in fewer than half of the samples taken, and only a small amount of cancer in each sample.

### PSA test

The PSA test is a blood test that measures the total amount of prostate specific antigen (PSA) in your 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.

### Other tests you might have

There are a number of other tests you might have to help decide if active surveillance is suitable for you.

#### 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're diagnosed with prostate cancer to find out whether the cancer has spread outside the prostate.

#### PSA density test

Your doctor might suggest you have a PSA density test to help find out how aggressive the prostate cancer is. This test is not done in every hospital.

You will have an ultrasound or an MRI scan to measure the size of your prostate. Then your PSA density is worked out by looking at your PSA level in relation to the size of your prostate. If you have a low PSA density, active surveillance might be an option for you.

### Free and total PSA test

This test measures the amount of two different types of PSA in your blood. It can help to give an idea of how likely it is that your cancer will grow. This test isn't done in every hospital.

### Other things to think about

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

- you're fit enough to have treatments such as surgery or radiotherapy
- you know about the advantages and disadvantages of being on active surveillance (see page 4)
- you've discussed other treatment options with your doctor or nurse and you're happy 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 pros and cons 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
- watchful waiting.

You might also be offered high intensity focused ultrasound (HIFU) or cryotherapy. These are newer than some of the other treatments for prostate cancer so we don't know as much about how well they work and the risk of side effects in the long term. Because of this, they're only available in specialist centres in the UK or as part of a clinical trial.



Read our **Tool Kit** fact sheets for more information about treatment options and their side effects.

If you're 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 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. We have more information about diagnosis in our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

You can also call our Specialist Nurses.



- There is a chance that your cancer might grow more quickly than expected and become harder to treat.
- 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.



**The idea of being on active surveillance was attractive because I didn't have to worry about side effects as I wasn't having any treatment. And I knew the cancer would be picked up and treated if it got dangerous.**

*A personal experience*

## What are the advantages and disadvantages?

What may be an advantage for one person might not be for someone else. If you're offered active surveillance, speak to your doctor or nurse before deciding whether to go on it – they'll be able to help you decide whether it's the right option for you. There's a list of questions on page 9 which you might find helpful.

There's 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're on active surveillance, you'll avoid the side effects of treatment.
- Active surveillance doesn't interfere with your everyday life as much as treatment might do.
- If tests show that your cancer might be growing, there are 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.

## What does active surveillance involve?

If you're 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 from hospital to hospital, but you may have:

- a PSA test every three to six months
- a digital rectal examination (DRE) every 6 to 12 months
- a prostate biopsy about a year after you were diagnosed, and then every few years
- an MRI scan if your PSA test or DRE results suggest the cancer is growing.

## 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'll 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're taking any medicines 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'll 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 if your PSA test or DRE results suggest the cancer is growing. The scan can help your doctor decide if you need another biopsy.

There are clinical trials looking at how useful MRI scans are at diagnosing and monitoring prostate cancer. A clinical trial is a type of medical research study that aims to find out new and improved ways of preventing, diagnosing and treating illnesses. Read more in our Tool Kit fact sheet, **A guide to prostate cancer clinical trials**. If you're interested in taking part in a clinical trial, speak to your doctor or nurse.

## Prostate biopsy

You might have a repeat prostate biopsy within 12 to 18 months of the first biopsy you had when you were diagnosed. Then you might have more biopsies every few years, depending on your hospital.

Repeat biopsies aren't done by every hospital – some will only do them if an MRI scan suggests the cancer is growing.

A prostate biopsy involves taking small pieces of prostate tissue to be looked at under the microscope to check for changes to your cancer. You may have a TRUS (trans-rectal ultrasound) guided biopsy or you might be offered a template biopsy. A template biopsy involves taking more tissue samples than a TRUS biopsy and is done in a different way.

 Read more about all these tests in our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

## Will I need treatment?

If the results of the tests show your cancer has grown, you'll 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're worried their cancer will spread. If you decide you do want treatment, speak to your doctor or nurse about your options.

## Are there any risks with active surveillance?

### Changes to your cancer

If you have active surveillance, there's 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's always a small chance that changes might be missed. This means there's 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've 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 or a scan about a year after 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's 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.



Read about staying healthy in our Tool Kit fact sheet, **Diet, physical activity and prostate cancer**.

### 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're 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 don't want to.



**I became very stressed at each PSA blood test. I was on active surveillance for four years and it was the stress that in the end prompted me to have treatment.**

*A personal experience*

### Are there any side effects?

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

But you might need to have prostate biopsies every few years. Biopsies can cause some short term side effects such as infection, and blood in the urine, semen or bowel movements.

About 3 in 50 men (six per cent) may get a serious infection after a TRUS biopsy, and your risk might increase with each biopsy. You will have antibiotics before your biopsy to help prevent infection. Read more about the side effects of prostate biopsy in our Tool Kit fact sheet, **How prostate cancer is diagnosed**.



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

## Dealing with prostate cancer

If you're dealing with prostate cancer, you might find it helpful to get some support, and there are things you can do to help yourself. Families may need support too, so this section might also be helpful for them.

### How can I help myself?

- Find out about your treatment options so you can decide what's right for you.
- Unload what's going around in your head – find someone you can talk to. It could be someone close, or someone trained to listen, like a counsellor or your medical team.
- Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like listening to music or breathing exercises.
- Set yourself goals and things to look forward to – even if they're just for the next few weeks or months.



- Find more strategies in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**.
- Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's Centres, and Penny Brohn Cancer Care, as well as your nearest cancer support centres.

### Eat well and stay active

A healthy, balanced diet is good for your general health and lowers your risk of other health problems. There is also some evidence that certain foods may slow down the growth of prostate cancer or lower the risk of it coming back after treatment.

Keeping active is also important for your general health. It can improve your physical strength and fitness, and it can lift your mood. Some research shows that physical activity can help to slow down the growth of prostate cancer. It can also help you stay a healthy weight, which may be important for lowering your risk of advanced prostate cancer.

Speak to your doctor or nurse before you start any kind of exercise plan. This is particularly important if you have any other health problems, such as heart disease or problems with your joints or muscles. They can give you advice and help you get started.



Read more about healthy eating and physical activity in our Tool Kit fact sheet, **Diet, physical activity and prostate cancer**.

### Who can help?

#### Your medical team

It could be useful to speak to your nurse, doctor or someone else in your medical team. They can help you understand your diagnosis and treatment options, listen to your concerns, and put you in touch with other people who can help.

#### Our Specialist Nurses

Our Specialist Nurses can answer your questions, help explain your diagnosis and go through your treatment options with you. They've 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:

- call our Specialist Nurses on 0800 074 8383
- email from our website at [prostatecanceruk.org](http://prostatecanceruk.org) (click 'We can help').

#### Trained counsellors

Counsellors are trained to listen and can help you to find your own answers and ways to deal with things. Many hospitals have counsellors or psychologists in their team who are specialists in helping people with cancer – your doctor or nurse at the hospital will be able to let you know if this is available.

There are different types of counselling available. Your GP may be able to refer you to a counsellor, or you can see a private counsellor. To find out more contact the British Association for Counselling & Psychotherapy.

### One-to-one support service

Our one-to-one support service is a chance to speak to someone who's been there and understands what you're going through. They can share their experiences and listen to yours. You could discuss treatment options or telling people about your cancer – whatever's important to you.

Our Specialist Nurses will try to match you with a trained volunteer with similar experiences. Family members can also speak to partners of men with prostate cancer.

To arrange it:

- call our Specialist Nurses on 0800 074 8383
- visit our website at [prostatecanceruk.org](https://prostatecanceruk.org) (click 'We can help').

### Our online community

Our online community is a place to talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question, or share an experience. It's a place to deal with prostate cancer together.

Sign up on our website at [prostatecanceruk.org](https://prostatecanceruk.org) (click 'We can help').

### Local support groups

At local support groups men get together to share their experiences of living with prostate cancer – you can ask questions, offload worries and know that someone understands what you're going through. Some groups have been set up by local health professionals, others by men themselves. Many also welcome partners, friends and relatives.

To find your nearest support group:

- visit our website at [prostatecanceruk.org](https://prostatecanceruk.org) (click 'We can help')
- ask your nurse
- call our Specialist Nurses on 0800 074 8383.



**I found talking to an experienced nurse on Prostate Cancer UK's helpline tremendously helpful.**

*A personal experience*

# 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?

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

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How often will I see my doctor or nurse?

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How often will I have a digital rectal examination (DRE)?

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Will I need more prostate biopsies – and how often?

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Will I need to have any scans?

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

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

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## What treatments could I have if my cancer grows?

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## What can I do to improve my overall health?

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### More information

#### British Association for Counselling & Psychotherapy

[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)

Telephone: 01455 883300

Information about counselling and details of therapists in your area.

#### CancerHelp UK

[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

Nurse helpline: 0808 800 4040

Patient information from Cancer Research UK.

#### Healthtalkonline

[www.healthtalkonline.org](http://www.healthtalkonline.org)

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

#### Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Telephone: 0808 808 00 00

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

#### Maggie's Centres

[www.maggiescentres.org](http://www.maggiescentres.org)

Telephone: 0300 123 1801

A network of drop-in centres for cancer information and support. Includes an online support group.

#### NHS Choices

[www.nhs.uk](http://www.nhs.uk)

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

#### NHS Direct Wales

[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

Telephone: 0845 46 47

Provides health advice 24 hours a day, and lists local health services in Wales, including GPs.

#### NHS Inform

[www.nhsinform.co.uk](http://www.nhsinform.co.uk)

Telephone: 0800 22 44 88

Provides health information and details of NHS and other support services in Scotland.

#### nidirect

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Information about government services in Northern Ireland, including health services.

#### Penny Brohn Cancer Care

[www.pennybrohncancercare.org](http://www.pennybrohncancercare.org)

Helpline: 0845 123 23 10

Runs courses and offers physical, emotional and spiritual support for people with cancer and those close to them.

## 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 to Z of medical words**, which explains some of the words and phrases used in this fact sheet.

Download and order our fact sheets and booklets from our website at [prostatecanceruk.org/publications](http://prostatecanceruk.org/publications) or call us on **0800 074 8383**.

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](http://prostatecanceruk.org)

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### Tell us what you think

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

[literature@prostatecanceruk.org](mailto:literature@prostatecanceruk.org)



## Speak to our Specialist Nurses

**0800 074 8383\***

**prostatecanceruk.org**

### Donate today – help others like you

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. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.
- £25 could give a man diagnosed with a prostate problem unlimited time to talk over treatment options with one of our Specialist Nurses.

To make a donation of any amount, please call us on **0800 082 1616**, 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](http://prostatecanceruk.org/terms)



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**Call our Specialist Nurses from Mon to Fri 9am - 6pm, Wed 10am - 8pm**

\* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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