

# Active surveillance



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This fact sheet is for men who want to know more about active surveillance, which is a way of monitoring localised (early) prostate cancer rather than treating it straight away. Your partner, family or friends might also find it helpful.

Active surveillance isn't the same as watchful waiting, which is a different way of monitoring prostate cancer. We explain the differences between them on page 2.

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

### Symbols

These symbols appear in this fact sheet:



Speak to our Specialist Nurses



Read our publications

## What is active surveillance?

Active surveillance is a way of monitoring localised prostate cancer (cancer that hasn't spread outside the prostate). If you go on active surveillance, you'll have regular tests to check 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 localised prostate cancer often grows slowly – or doesn't grow at all – and may have a low risk of spreading. So it may never cause you any problems or affect how long you live. Because of this, you might not need any treatment.

Treatments for prostate cancer, such as surgery, radiotherapy or hormone therapy, can cause side effects. These can include urine, bowel and erection problems, and fatigue. For some men these side effects may be long-term and can have a big impact on daily life.

If you decide to go on active surveillance, you won't have any treatment, so you'll avoid or delay the side effects of treatment. Instead, you'll have regular check-ups and tests. If these show that your cancer may be growing, or if you decide you want treatment, you will be offered treatment that aims to cure your cancer. Many men on active surveillance will never need treatment.



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

Active surveillance is often confused with another way of monitoring prostate cancer, called watchful waiting. The aim of both is to avoid unnecessary treatment, but the reasons for having them are different. Make sure you know which one you've been offered and why.

#### Active surveillance

- It is suitable for some men with cancer that hasn't spread outside the prostate (localised cancer), who can still have treatment that aims to cure their cancer.
- If you need treatment in the future, it will aim to cure your cancer.
- It involves more regular hospital tests than watchful waiting, such as prostate specific antigen (PSA) tests, magnetic resonance imaging (MRI) scans and prostate biopsies (see page 4).

#### Watchful waiting

- 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 if treatment would cause more problems than the cancer itself.
- If you do have treatment in the future, it will aim to control the cancer and manage any symptoms, rather than aim to cure it.
- It can be used in men with localised prostate cancer, or in men whose cancer has spread to other parts of the body (locally advanced or advanced cancer).
- It involves fewer tests than active surveillance, but the cancer will still be monitored. These check-ups usually take place at the GP surgery rather than at the hospital.

### Other terms you might hear

Some people use names such as 'active monitoring' and 'wait and see' to describe both active surveillance and watchful waiting. These 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 hasn't spread outside the prostate (localised prostate cancer) and has a low risk of spreading (low risk cancer).

It's also sometimes suitable for men with prostate cancer that has a medium risk of spreading (intermediate risk cancer), 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 that has a high risk of spreading (high risk cancer), active surveillance won't be recommended 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:

- the size of your cancer
- how far your cancer has spread (its stage)
- how quickly it might grow (how aggressive it is).

They will work out your risk group to see if active surveillance is an option for you.

#### Low risk

Your cancer may be low risk if:

- your PSA level is less than 10 ng/ml, **and**
- your Gleason score is 6 (grade group 1), **and**
- the stage of your cancer is T1 to T2a.

## Intermediate (medium) risk

Your cancer may be intermediate risk if:

- your PSA level is between 10 and 20 ng/ml, **or**
- your Gleason score is 7 (grade group 2 or 3), **or**
- the stage of your cancer is T2b.

Your doctor will also look at the amount of cancer found in your prostate biopsy.

You can read more about what your test results mean and how to work out your risk group in our fact sheet, **Localised prostate cancer**.



## MRI scan

You may also have an MRI scan to help decide if active surveillance is suitable for you. This uses magnets to create a detailed picture of your prostate and the surrounding tissues.

You may have already had an MRI scan to help diagnose your prostate cancer. If not, you may need one after you've been diagnosed, to make sure the cancer hasn't spread outside your prostate and isn't likely to grow quickly. Active surveillance will only be an option if the cancer hasn't spread.

## 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 if your cancer starts to grow
- you know about the advantages and disadvantages of being on active surveillance
- you've discussed other treatment options, including the possible side effects and risks, 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 treatment that is suitable for you. Your doctor or nurse should discuss the advantages and disadvantages of all the different treatment

options with you. This should help you decide whether to go on active surveillance or start treatment straight away.

Other treatment options include:

- surgery to remove the prostate (radical prostatectomy)
- external beam radiotherapy – which uses X-ray beams to kill the cancer cells
- brachytherapy – a type of internal radiotherapy
- watchful waiting (see page 2)
- high-intensity focused ultrasound (HIFU) or cryotherapy, but these are less common.

With some of the above treatments, you may also need to have a treatment called hormone therapy. Read our other fact sheets for more information about all of these treatment options and their side effects.

## 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 and treatment in our other fact sheets. You can also call our Specialist Nurses, or chat to them online.



## What are the advantages and disadvantages?

Deciding whether or not to go on active surveillance is a personal choice. What may be important to one person might not be so important to someone else. If you're offered active surveillance, speak to your doctor or nurse before deciding whether to go on it – they can help you decide whether it's right for you. There's a list of questions on page 9 that 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 won't affect your everyday life as much as treatment might.
- If tests show that your cancer might be growing, there are treatments available that aim to cure your cancer.

## 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 treat – but this is very uncommon.
- 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 – but you can change your mind and have treatment instead if this is a problem.



**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.**

*A personal experience*

## 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.

Depending on your hospital, you may have:

- PSA tests
- MRI scans
- digital rectal examinations (DRE)
- prostate biopsies.

If your test results show that your cancer might be growing, you will be offered further tests to check on the cancer. If any changes are found, you can have treatment that aims to get rid of the cancer – such as surgery or radiotherapy.

## PSA test

This 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 by prostate cancer cells.

You will have had a PSA test to help diagnose your cancer. It's also a useful test for monitoring prostate cancer. It's normal for your PSA level to go up a little as you get older and your prostate gets bigger. And other things can cause it to rise, like an infection, recent ejaculation, vigorous exercise, and some medicines or supplements. But if your PSA level rises faster than expected, this could be a sign that your cancer is growing.

Your doctor may look at the following.

## PSA velocity

If your PSA level rises, your doctor will look at how quickly it is rising – you may hear this called your PSA velocity. It is usually recorded as the change in your PSA level per year. For example, if your PSA level has increased from 3 to 4 over the last 12 months, your PSA velocity would be 1 ng/ml/year.

## PSA doubling time

Your doctor may talk to you about your PSA doubling time. This is the time it takes for your PSA levels to double. For example, if your PSA level has increased from 3 to 6 in one year, your PSA doubling time would be 1 year.

## PSA density

Your doctor may also look at your PSA density. For this you will have an ultrasound or an MRI scan to measure the size of your prostate.

Your PSA density is then worked out by dividing your PSA level by the volume (size) of your prostate.

If your doctor is concerned by any of these test results, they might recommend an MRI scan or a prostate biopsy to check if the cancer is growing.

### Booking your PSA test

If you choose to go on active surveillance, you may have your PSA tests at your local hospital, or you may need to book these tests yourself at your GP surgery. This varies from hospital to hospital.

Your doctor or nurse may send you a letter saying how often you should have PSA tests. But you might not get reminders, so check with your doctor so you know how often you need one. Give yourself plenty of time to book them, as hospitals and GP surgeries can be very busy and you may not be able to get an appointment straight away.

### MRI scan

You should have an MRI scan when you first go on active surveillance to make sure your cancer hasn't spread outside the prostate. You may then have regular MRI scans, although this will depend on your hospital. Your doctor may also suggest having an MRI scan if your PSA test or DRE results suggest your cancer might be growing. The scan can help your doctor decide if you need a biopsy.

### Digital rectal examination (DRE)

This is where the doctor feels your prostate through the wall of the back passage (rectum). A normal prostate should feel soft and smooth. Your doctor will feel your prostate for any changes, such as hard or lumpy areas, that could suggest the cancer is growing.

### Prostate biopsy

Once you start active surveillance, you may only have another biopsy if other tests suggest your cancer is growing. Your PSA level might rise a little bit, even if your cancer isn't growing. But if it rises more quickly than expected, your doctor may suggest having a biopsy. You may have an MRI scan before you have a biopsy, but that will depend on your hospital.

If you do have a biopsy that shows your prostate cancer has grown, then your doctor may recommend you have treatment. This treatment will usually aim to get rid of the cancer.

Read more about these tests in our fact sheet,



**How prostate cancer is diagnosed.**

### How often will I have tests?

How often you will have tests and what tests you will be offered will be different in every hospital. The table below is a general guide. Your doctor will tell you how often you will have tests.

Year of active surveillance	Tests
First year	<ul style="list-style-type: none"><li>• PSA test: every three to four months.</li><li>• DRE: after 12 months.</li><li>• MRI scan: after 12 to 18 months.</li></ul>
Second year onwards	<ul style="list-style-type: none"><li>• PSA test: every six months.</li><li>• DRE: every 12 months.</li></ul>

### Will I need treatment in the future?

If the results of the tests show your cancer is growing, you'll be offered treatment that aims to get rid of the cancer – for example, surgery or radiotherapy.

You can decide to have treatment at any time, no matter how long you have been on active surveillance. Some men decide they want to have treatment even though there are no signs of any changes. If you decide you do want treatment, speak to your doctor or nurse.



## Is active surveillance safe?

Research shows active surveillance is a safe way for men who are diagnosed with low risk prostate cancer to avoid or delay unnecessary treatment. And you have the same chances of living for 10 years or more as you would if you chose to have treatment with surgery or radiotherapy.

### Picking up changes to your cancer

If you go on active surveillance, there's a chance that your cancer could grow. But the risk of it growing without being picked up is very low. And the tests used to monitor your cancer should find any changes early enough to treat it.

There is a very 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 completely.

This can happen if:

- the tests used in active surveillance miss changes in your cancer, or
- the tests used to diagnose your prostate cancer didn't find some areas of faster-growing cancer.

But this is very uncommon and you will have regular tests to check on the cancer and make sure it isn't growing more quickly than expected. Talk to your doctor or nurse if you are worried about the risk of your cancer growing.



**I was on active surveillance for five years before a regular check showed my cancer was becoming more aggressive. So I decided to have a radical prostatectomy. Six years later, my PSA level is undetectable.**

A personal experience

## Concerns about not having treatment

Many men with low risk localised prostate cancer choose to go on active surveillance when they are first diagnosed. But active surveillance isn't for everyone. You might find it difficult not having treatment for 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.

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

### Changes to your health

There's a chance that your general health could change while you are on active surveillance. This could 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 your prostate, as an operation might not be safe for you.

You can lower your risk of many health problems by eating healthily and doing regular exercise.



Read more in our fact sheet, **Diet and physical activity for men with prostate cancer.**

### 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, like urinary problems or erection problems.

You might need to have prostate biopsies while you are on active surveillance. Biopsies can cause some short-term side effects, such as infection, and blood in the urine, semen or bowel movements. Around 3 in 100 men (three per cent) may get a serious infection after a trans-rectal ultrasound (TRUS) guided biopsy. The risk of infection is lower after a transperineal biopsy, which is another way of doing a prostate biopsy. And many hospitals now do MRI scans instead of regular prostate biopsies.



Read more about the side effects of prostate biopsy in our fact sheet, **How prostate cancer is diagnosed**.

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. Or you could speak to our Specialist Nurses.



## Dealing with prostate cancer

Some men say being diagnosed with prostate cancer changes the way they think and feel about life. You might feel scared, worried, stressed, helpless or even angry.

At times, lots of men with prostate cancer get these kinds of thoughts and feelings. But there's no 'right' way to feel and everyone reacts in their own way.

This section suggests some things you can do to help yourself and people who can help. Families can also find this a difficult time and they may need support and information too. They may want to read our booklet, **When you're close to a someone with prostate cancer: A guide for partners and family**.



### How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

### Look into your treatment options

Find out about the different treatments you could have. Bring a list of questions to your doctor or nurse. And ask about the side effects of each treatment – this will help you decide whether treatment or active surveillance is right for you.

### Talk to someone

Share what you're thinking – find someone you can talk to. It could be someone close or someone trained to listen, like a counsellor or your doctor or nurse. People involved in your care should be able to help with any questions or concerns you might have.

### Set yourself some goals

Set yourself goals and things to look forward to – even if they're just for the next few weeks or months.

### Look after yourself

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like breathing exercises or listening to music. If you're having difficulty sleeping, talk to your doctor or nurse.

### Eat a healthy, balanced diet

Eating well is good for your general health. It can also help you stay a healthy weight, which may be important for men with prostate cancer. For more information, read our fact sheet, **Diet and physical activity for men with prostate cancer**.



### Be as active as you can

Keeping active can improve your physical strength and fitness, and can lift your mood. We don't know for sure if physical activity can help slow the growth of prostate cancer. But it can help you stay a healthy weight, which may help to lower your risk of advanced prostate cancer. Even a small amount of physical activity can help. Take things at your own pace. Read more in our fact sheet, **Diet and physical activity for men with prostate cancer**.



### Smoking

Some research suggests that smoking makes prostate cancer more likely to grow and spread to other parts of the body. And the more you smoke, the greater the risk. There's lots of support available to help you stop smoking. Talk to your doctor or nurse, or visit [www.nhs.uk/smokefree](http://www.nhs.uk/smokefree)

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's Centres, Penny Brohn UK, or your nearest cancer support centre. You can also find more ideas in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**.



### Check out our online 'How to manage' guides

Our interactive guides have lots of practical tips to help you manage symptoms and side effects. We have guides on fatigue, sex and relationships, urinary problems, and advanced prostate cancer. Visit [prostatecanceruk.org/guides](http://prostatecanceruk.org/guides)

### Who else can help?

#### Your medical team

It may be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with other people who can help.



#### Our Specialist Nurses

Our Specialist Nurses can help with any questions and explain your diagnosis and treatment options. They have time to listen, in confidence, to any concerns you or those close to you have.

#### Trained counsellors

Counsellors are trained to listen and can help you find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer – ask your doctor or nurse at the hospital if this is available. Your GP may also be able to refer you to a counsellor, or you could see a private counsellor. To find out more, contact the British Association for Counselling & Psychotherapy.

#### Our 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 can discuss whatever's important to you. Our Specialist Nurses will try to match you with someone with similar experiences.



### 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.

### Local support groups

At local support groups, men get together to share their experiences of living with prostate cancer. You can ask questions, share 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 out more about any of the above, visit [prostatecanceruk.org/get-support](http://prostatecanceruk.org/get-support) or call our Specialist Nurses on 0800 074 8383.





# 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.

Am I going on active surveillance or watchful waiting?

How often will I have my PSA level checked?

Who will be in charge of booking my PSA tests?

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

Is there a way I can record and track my PSA levels?

How often will I see my doctor or nurse?

Will I have other regular tests or scans? If so, which ones and how often?

What test results would lead you to recommend treatment? Are there any specific results that mean I should have further tests?

What treatments could I have if my cancer grows?

What can I do to improve my general health?

## More information

### British Association for Counselling & Psychotherapy

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

Telephone: 01455 883 300

Information about counselling and details of therapists in your area.

### Cancer Research UK

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

Telephone: 0808 800 4040

Patient information from Cancer Research UK.

### Healthtalk.org

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

Watch, listen to and read personal experiences of men with prostate cancer and other health problems.

### Macmillan Cancer Support

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

Telephone: 0808 808 0000

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

Drop-in centres for cancer information and support, and an online support group.

### NHS website

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

Information about conditions, treatments and lifestyle, 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.scot](http://www.nhsinform.scot)

Telephone: 0800 22 44 88

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 UK

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

Telephone: 0303 3000 118

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

## About us

Prostate Cancer UK has a simple ambition: to stop men dying from prostate cancer – by driving improvements in prevention, diagnosis, treatment and support.



This fact sheet is part of the Tool Kit. You can order more 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** 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**

**This publication was written and edited by** our Health Information team.

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- Evelyn Pearson, Clinical Nurse Specialist, Stockport NHS Foundation Trust
- Our Specialist Nurses
- Our Volunteers.

### Tell us what you think

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

**yourfeedback@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, over 47,000 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/donate** or text **PROSTATE** to **70004**<sup>†</sup>.

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

<sup>†</sup> 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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**t** Follow us on Twitter: **@ProstateUK**

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**Call our Specialist Nurses from Monday to Friday 9am - 6pm, Wednesday 10am - 8pm**

\* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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