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 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 another way of monitoring prostate cancer. We explain the differences between the two 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.

What is active surveillance?

Active surveillance is a way of monitoring prostate cancer that hasn’t spread outside the prostate (localised prostate cancer). If you go on active surveillance, you will 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 or radiotherapy, can cause side effects. These can include leaking urine (incontinence), bowel problems, and erection problems. 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 unless your tests show that your cancer may be growing, or you decide you want treatment – so you’ll avoid or delay the side effects of treatment. If there are signs your cancer may be growing, you will be offered treatment that aims to cure your cancer. 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 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 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. These 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.

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 or less, **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, **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 working out your risk group in our fact sheet, [Localised 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
An MRI (magnetic resonance imaging) scan uses magnets to create a detailed picture of your prostate and the surrounding tissues. You might have an MRI scan to check that your cancer hasn’t spread outside the prostate.

PSA density test
Your doctor might also look at your PSA density to help find out how aggressive the prostate cancer is.

For this 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 and the size of your prostate. If you have a low PSA density, active surveillance might be an option for you.

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 (see below)
• you’ve discussed other treatment options with your doctor or nurse and you’re happy to go on active surveillance.

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
• high-intensity focused ultrasound (HIFU) or cryotherapy, but these are less common.

Read our fact sheets for more information about 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 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 8 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 won’t affect your everyday life as much as treatment would.

• 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.

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 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 that aims to get rid of the cancer – such as surgery or radiotherapy.

Depending on your hospital, you may have:

• PSA tests

• digital rectal examinations (DRE)

• MRI scans

• prostate biopsies.

If your test results show that your cancer might be growing, you will be offered further tests to check on the cancer.

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. And it’s also a useful test for 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.

A rise in your PSA level could be a sign that your cancer is growing. But a number of other things can also cause it to rise, including age and infection. Let your doctor know if you’re taking any medicines or supplements, as they might affect your PSA level too.

If your PSA level rises more quickly than expected, then your doctor might recommend a prostate biopsy or an MRI scan to check if the cancer is growing.
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. Your doctor will feel your prostate for any changes, such as hard or lumpy areas, which could suggest the cancer is growing.

MRI scan
You might have an MRI scan when you first go on active surveillance to make sure your cancer hasn’t spread outside the prostate. You might then have regular MRI scans, depending on your hospital. Your doctor may also suggest having an MRI 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.

Prostate biopsy
You might have another prostate biopsy 12 to 18 months after you first start on active surveillance. Then you might have another biopsy every few years, depending on your hospital. Your doctor might also suggest having a biopsy if your other test results suggest your cancer might be growing.

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 these tests in our fact sheet, How prostate cancer is diagnosed.

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.

Some men decide they want to have treatment even though there are no signs of any changes. You can decide to have treatment at any point. If you decide you do want treatment, speak to your doctor or nurse.

Does active surveillance have any risks?
Changes to your cancer
If you go on 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 treatment that aims to cure the cancer, such as surgery or radiotherapy.

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. But this isn’t very common.

Sometimes, men who’ve been diagnosed with low risk prostate cancer actually have a more aggressive cancer that needs to be treated to stop it spreading outside the prostate. Prostate biopsies only take small pieces of tissue from the prostate so it’s possible that a biopsy might miss an area of faster-growing cancer. This is uncommon, and you will have regular tests to check on the cancer and make sure it isn’t growing more quickly than expected.

The risk that your cancer will grow without being picked up is very low. Research shows active surveillance is a safe way for men who are diagnosed with low risk prostate cancer to avoid or delay unnecessary treatment. Men with low risk localised prostate cancer who go on active surveillance have the same chances of living for 10 years or more as men who choose to have treatment with surgery or radiotherapy. It’s important to think about this when deciding whether to have treatment straight away or to go on active surveillance.

Talk to your doctor or nurse if you are worried about the risk of your cancer growing.
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, 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 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.

But 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 TRUS biopsy.

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. If you are dealing with prostate cancer 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 that you’re supposed to feel and everyone reacts in their own way.

There are 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 too. This section might also be helpful for them.

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 that are available to you. 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. Your GP, nurse or other health professionals involved in your care should be able to answer 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.
Eat a healthy, balanced diet
Eating well is good for your general health. There is some evidence that certain foods may help slow down the growth of 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. Some research suggests that physical activity may help slow down the growth of prostate cancer. It can also 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. For more information, read our fact sheet, Diet and physical activity for men with prostate cancer.

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.

I found it very important to remain positive, and made changes to my life such as improving my diet and taking up new interests.
A personal experience

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 answer your questions and explain your diagnosis and treatment options. They’ve got 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 can 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 free 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 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.

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<td><strong>Who will check my PSA level and give me the results?</strong></td>
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<td><strong>How often will I see my doctor or nurse?</strong></td>
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<td><strong>How often will I have a digital rectal examination (DRE)?</strong></td>
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<td><strong>Will I need more prostate biopsies – and how often?</strong></td>
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<td><strong>How quickly would my PSA level need to rise for you to recommend treatment?</strong></td>
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<td><strong>What treatments could I have if my cancer grows?</strong></td>
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<td><strong>What can I do to improve my general health?</strong></td>
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More information

British Association for Counselling & Psychotherapy
www.bacp.co.uk
Telephone: 01455 883 300
Information about counselling and details of therapists in your area.

Cancer Research UK
www.cancerresearchuk.org
Telephone: 0808 800 4040
Patient information from Cancer Research UK.

Healthtalk.org
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
Telephone: 0808 808 0000
Practical, financial and emotional support for people with cancer, their family and friends.

Maggie's Centres
www.maggiescentres.org
Telephone: 0300 123 1801
Drop-in centres for cancer information and support. Includes an online support group.

NHS Choices
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
Telephone: 0845 46 47
Provides health advice 24 hours a day, and lists local health services in Wales.

NHS Inform
www.nhsinform.scot
Telephone: 0800 22 44 88
Provides health information and details of NHS and other support services in Scotland.

nidirect
www.nidirect.gov.uk
Information about government services in Northern Ireland, including health services.

Penny Brohn UK
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 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 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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- Our Specialist Nurses
- Our Volunteers.

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If you have any comments about our publications, you can email: literature@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/donate 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