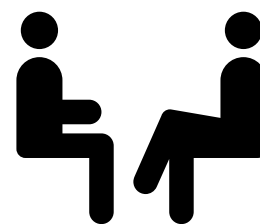


# Watchful waiting



## In this fact sheet:

- What is watchful waiting?
- Who can go on watchful waiting?
- Can I have treatment instead?
- What are the advantages and disadvantages of watchful waiting?
- What does watchful waiting involve?
- Making a decision about treatment
- Dealing with prostate cancer
- Questions to ask your doctor or nurse
- More information
- About us



This fact sheet is for anyone who wants to know more about watchful waiting, which is a way of monitoring prostate cancer. Your partner, family or friends might also find it helpful.

Watchful waiting isn't the same as active surveillance, which is another way of monitoring prostate cancer. We explain the differences between them on page 2.

Each hospital or GP surgery 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 to guide you to more information:

-  Speak to our Specialist Nurses
-  Read our publications

## What is watchful waiting?

Watchful waiting is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term, and avoid treatment unless you get symptoms.

It might seem strange not to have treatment, but prostate cancer often grows slowly and may never cause any problems or symptoms.

Also, many treatments for prostate cancer, like radiotherapy, surgery or hormone therapy, can cause side effects. These include urinary, erection and bowel problems, and fatigue. For some men, these side effects may be long-term and can have a big impact on their lives.

If you go on watchful waiting, you'll avoid these side effects, as you won't have any treatment unless your cancer starts to cause problems.

Many men on watchful waiting will never need any treatment for their prostate cancer. But for some men, their cancer may grow more quickly than expected and they may start to get symptoms, such as urinary problems or bone pain. If this happens, you can start treatment to control the cancer and improve your symptoms (see page 4).



## What is the difference between watchful waiting and active surveillance?

Watchful waiting is often confused with active surveillance, which is another way of monitoring prostate cancer. The aim of both is to avoid having unnecessary treatment, but the reasons for having them are different. Check with your doctor which one you're being offered.

### Watchful waiting

- If you do have treatment at any point, it will usually aim to control the cancer and manage any symptoms, rather than cure it.
- It's generally suitable for men with other health problems who may not benefit from treatment such as surgery or radiotherapy, or whose cancer may never cause problems during their lifetime.
- It involves fewer tests than active surveillance. These check-ups usually take place at the GP surgery rather than at the hospital.

### Active surveillance

- If you need treatment at any point, it will usually aim to cure the cancer.
- It is only suitable for men with slow-growing cancer that hasn't spread outside the prostate (localised cancer), and who would benefit from treatment such as surgery or radiotherapy if they needed it.
- It involves more regular hospital tests than watchful waiting, such as magnetic resonance imaging (MRI) scans and prostate biopsies.

### Other terms you might hear

Some people use terms such as 'active monitoring', 'deferred therapy', 'watch and wait' and 'wait and see' to describe both watchful waiting and active surveillance. 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 watchful waiting?

Watchful waiting may be suitable for you if your prostate cancer isn't causing any symptoms or problems, and:


- treatments may not help you live longer
- your prostate cancer isn't likely to cause any problems during your lifetime, or shorten your life.

It's important that you discuss other treatment options with your doctor and you're happy to go on watchful waiting.

## Can I have treatment instead?

There will be treatment options available to you if you don't want to go on watchful waiting. These will depend on whether your cancer has spread and how quickly it might be growing, as well as any other health problems you might have.

If at any time you decide that you want treatment, talk to your doctor or nurse about all your options. They can explain your test results and discuss your treatment options with you.

You should have all the information you need before making a decision. Read more about making a decision on page 4. We have more information about diagnosis and treatment in our other fact sheets. You can also speak to  our Specialist Nurses.

## What are the advantages and disadvantages of watchful waiting?

What may be important to one person might not be so important to someone else. Speak to your doctor or nurse about your own situation and the things that are important to you.

### Advantages

- You'll avoid the side effects of treatment while you're on watchful waiting.
- You won't need to have regular MRI scans or prostate biopsies.
- If you get symptoms, treatments such as hormone therapy can help manage them. But many men never need any treatment.

### Disadvantages

- There is a chance that the cancer may change and grow. If this happens you can start treatment, such as hormone therapy, to shrink the cancer and treat the symptoms. Hormone therapy can't cure the cancer, but it can keep it under control, sometimes for several years.
- You might worry about the cancer growing and about getting symptoms. But remember that men having treatment often have these worries too.
- Partners, family members or friends might worry and find it hard to understand why you aren't having treatment.



**I trust my consultant and his team to monitor my cancer. I'm in good hands and can forget about it between check-ups.**

*A personal experience*

## What does watchful waiting involve?

If you're on watchful waiting you will have tests to monitor your cancer. You won't have any treatment unless you get symptoms.

You'll normally have a prostate specific antigen (PSA) blood test at your GP surgery or hospital clinic every 6 to 12 months. This will help to check for any changes to your prostate cancer.

### The PSA test

The PSA test is a blood test that measures the amount of a protein called prostate specific antigen (PSA) in your blood. PSA is produced by normal cells in your prostate, and also by prostate cancer cells. The test is a useful way of monitoring prostate cancer.

You may have other tests, depending on your symptoms. For example, you may have digital rectal examinations (DRE) and other blood tests. You probably won't need to have regular scans or prostate biopsies. To find out more about these tests, read our fact sheet, **How prostate cancer is diagnosed**.



If any changes are picked up by these tests or you get any new or different symptoms, you may be given an appointment with a doctor or nurse at the hospital.

## What symptoms should I look out for?

You should let your GP or doctor or nurse at the hospital know if you notice any symptoms or changes to your health. Things to look out for include:

- any changes to your urinary habits, for example needing to urinate (wee) more often, especially at night
- problems urinating, such as a weak or slow flow
- blood in your urine
- new aches and pains in your back or bones
- fatigue (extreme tiredness)
- unexplained weight loss
- new swelling in your legs.

Ask your doctor or nurse if there are any other symptoms or changes to your health that you should look out for, as well as who to contact about them.

### What happens if I get symptoms?

If you start to notice any of these symptoms you might need more tests to see if your cancer has spread, and you may be offered treatment.

The most common treatment to control the cancer and help improve symptoms is hormone therapy. This shrinks the cancer cells, wherever they are in the body, and slows down the growth of the cancer. However, hormone therapy can cause side effects. Read more in our booklet,



#### **Living with hormone therapy: A guide for men with prostate cancer.**

There are also treatments available to manage specific symptoms. For example, if your prostate cancer has spread to the bones (advanced prostate cancer) it can cause bone pain. Treatments for bone pain include pain-relieving drugs and radiotherapy.

Read more about managing the symptoms of advanced prostate cancer in our booklet,



#### **Advanced prostate cancer: Managing symptoms and getting support.**

## Making a decision about treatment

It can be difficult deciding whether to go on watchful waiting or have treatment. Discuss all your treatment options with your doctor or nurse – they'll be able to help you think about the advantages and disadvantages. Give yourself time to think about what is right for you. Make sure you have all the information you need, and have the details of someone to contact if you have any questions.

You can ask for a second opinion about your treatment from a different doctor, if you want one. You don't have a legal right to a second opinion, but most doctors will be happy for you to have one and will refer you to a different doctor.



## It can be scary, but I found that thinking positively and looking after myself helped me and those around me.

A personal experience

### Making the most of your appointment

There can be a lot of information to take in at your appointments. These suggestions may help you get the most out of them.

- Write down any questions you have before your appointment and take them with you. There are some suggestions on page 6.
- Take a notebook and pen, so you can write down what's said.
- It can help to take someone with you, to listen and discuss things with later. They could also make notes for you.
- Take our booklets and fact sheets with you – you could use them to help you talk things through with your doctor or nurse.
- Ask your doctor if you can record the appointment using your phone or another recording device. You have the right to record your appointment, as it's your personal data.

You might also find it helpful to talk things through with someone else. There are suggestions of who can help on page 5.

### What if I change my mind?

If you're on watchful waiting but decide you want treatment, speak to your doctor or nurse. They can discuss any suitable treatments with you.

## Dealing with prostate cancer

Having prostate cancer can change the way you feel about life. You might feel scared, stressed or even angry. There's no 'right' way to feel and everyone reacts differently. There are things you can do to help yourself and people who can help. Your loved ones may also need support – this section might be helpful for them too.

### How can I help myself?

#### Look into your treatment options

If you can't decide between watchful waiting and treatment, speak to your nurse or doctor. They can help you understand your treatment options.

#### Talk to someone

This could be someone close or someone trained to listen, like a counsellor or your doctor or nurse.

#### Set yourself some goals

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

#### Look after yourself

Learn some techniques to relax and manage stress, such as breathing exercises or listening to music.

#### Healthy eating and keeping active

A balanced diet and keeping active is good for your general health. It can also help you stay a healthy weight, which may be important for men with prostate cancer. If you start treatment in the future, a healthy lifestyle could also help with some of the side effects. Speak to your doctor or nurse before you start any new exercise.



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

#### 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](https://prostatecanceruk.org/guides)



For more ideas read our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**. You could also contact Macmillan Cancer Support, Maggie's, Penny Brohn UK or your nearest cancer support centre.

### Who else can help?

#### Your medical team

It may help to speak to your doctor or nurse. They can explain your diagnosis, listen to your concerns, and help you get support.

#### Trained counsellors

Many hospitals have counsellors or psychologists who specialise in helping people with cancer. You could also refer yourself for free counselling or see a private counsellor.

#### Support groups

At support groups, men get together to share their experiences of living with prostate cancer.

#### Hospices

Hospices don't just care for people at the end of their life – you may be able to use their services while still living at home. They can provide treatment to manage pain, as well as emotional and spiritual support, practical and financial advice, and support for families. Your GP, doctor or nurse can refer you to a hospice service or community palliative care team.

#### Prostate Cancer UK services

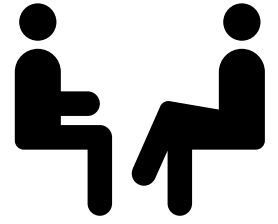
We have a range of services to help you deal with prostate cancer, including:

- **our Specialist Nurses**, who can help with any questions in confidence
- **our one-to-one support service**, where you can speak to someone who understands what you're going through
- **our online community**, a free forum to ask questions or share experiences
- **our fatigue support**, speak to our Specialist Nurses about ways to help manage fatigue.

To find out more about any of the above, visit [prostatecanceruk.org/get-support](https://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.

Why is watchful waiting suitable for me?

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Are any treatments suitable for me?

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What tests will I need, and how often?

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What signs and symptoms should I look out for?

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If I notice any new symptoms, who should I contact?

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When might I start to have treatment and what would this involve?

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## 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

Information about cancer and clinical trials.

### healthtalk.org

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

Watch, listen to or 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

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

Telephone: 0300 123 1801

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

### Penny Brohn UK

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

Telephone: 0303 3000 118

Courses and 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.

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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Our Health Information team.

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- Chris Parker, Consultant Clinical Oncologist, The Royal Marsden NHS Foundation Trust
- Nona Toothill, Urology Clinical Nurse Specialist, Airedale 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](mailto: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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To be reviewed December 2022

**Call our Specialist Nurses from Monday to Friday 9am - 5pm, Wednesday 10am - 5pm**

\* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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