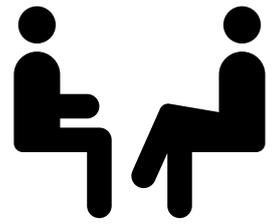


# Watchful waiting



## In this fact sheet:

- What is watchful waiting?
- Who can go on watchful waiting?
- Can I have treatment instead of watchful waiting?
- 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 men who want 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 your cancer. We explain the differences between the two 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 is often slow growing and may not cause any problems or symptoms in your lifetime. Also, many treatments for prostate cancer, like radiotherapy or surgery (radical prostatectomy), can cause side effects. These include problems getting or keeping an erection (erectile dysfunction), leaking urine (incontinence) and bowel problems. For some men these side effects may be long-term and may have a big impact on their daily lives.

If you go on watchful waiting, you won't have any treatment unless you get symptoms, so you'll avoid these side effects. Many men on watchful waiting won't need any treatment for their prostate cancer. But for some men, their cancer may grow more quickly than expected.

- If your cancer does grow and you start to get symptoms, you can start treatment to control the cancer and help manage symptoms (see page 4). Possible symptoms include problems urinating (peeing) and bone pain.

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## 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 to live longer
- you have other health problems which mean you might not be fit enough for treatments such as radiotherapy or surgery
- your prostate cancer isn't likely to cause any problems during your lifetime, or shorten your life.

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

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## Can I have treatment instead of watchful waiting?

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.

Watchful waiting isn't for everyone. You might find it difficult not having treatment for your prostate cancer and worry that it will change or spread.

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 is the difference between watchful waiting and active surveillance?

Watchful waiting is often confused with active surveillance – 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.

### Watchful waiting

- If you do have treatment at any point, it will usually 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.

### Active surveillance

- If you decide to have treatment at any point, it will usually aim to cure the cancer.
- It is suitable for most men with cancer that is contained in the prostate (localised cancer), and who could cope with treatments such as surgery or radiotherapy if they needed it.
- It usually involves more regular hospital tests than watchful waiting, such as prostate biopsies and magnetic resonance imaging (MRI) scans.

### Other terms you might hear

Some people use terms such as 'active monitoring' 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.

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

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

### Advantages

- As you won't have treatment while you're on watchful waiting, you'll avoid the side effects of treatment.
- You won't need to have regular prostate biopsies.
- There are treatments available to control your cancer and manage your symptoms if you start to get symptoms. But many men never need treatment at all.

### Disadvantages

- There is a chance that the cancer may change and grow. If this happens you can start treatment such as hormone therapy to control the cancer and treat the symptoms.
- Some men may worry about their cancer growing and about getting symptoms.
- Partners and family members may worry about their loved one and find it hard to understand why they aren't having treatment.



**I trust my consultant and his team to monitor my condition. I am 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 used to help diagnose and monitor prostate cancer.

You might also have digital rectal examinations (DRE) and other blood and urine tests. You probably won't need to have 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 have 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 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
- 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. You can read more about this



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 it can cause bone pain.

Treatments to manage bone pain include pain-relieving drugs such as paracetamol or ibuprofen, or stronger drugs such as codeine or morphine. You may also be offered radiotherapy to shrink the cancer and reduce symptoms, or drugs called bisphosphonates.

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



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

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## 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 pros and cons. Give yourself time to think about what is right for you. Make sure you've got 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 thinking positively and looking after yourself will help you and those around you too.**

*A personal experience*

## Making the most of your appointment

These suggestions may help you get the most out of your appointments.

- Write down any questions you have before your appointment and take them with you. There are some suggestions on page 6.
- There can be a lot to take in at your appointments. You might find it helpful to take someone with you, to listen and discuss things with later.
- Take our booklets and fact sheets to your appointment with you. Use them as a way to talk things through with your doctor or nurse.
- Take a notebook and pen, so you can write down what's said.

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.

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## Dealing with prostate cancer

Being diagnosed with prostate cancer can change how you feel about life. If you or your loved one is dealing with prostate cancer you may feel scared, stressed or even angry. There is no 'right' way to feel and everyone reacts differently. There are things you can do to help yourself and people who can help.

## How can I help myself?

- **Look into your treatment options.** If you can't decide between having treatment and going on watchful waiting, speak to your nurse or doctor. They can tell you about the treatment options available to you and any side effects so you know what to expect and how to manage them.
- **Talk to someone.** This could be someone close, or someone trained to listen, like a counsellor or your medical team.
- **Set yourself some 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 learn some techniques to manage stress and to relax, like breathing exercises or listening to music. If you have other health problems, make sure these are being treated. You can always ask your GP to review your medicines, or for a general check-up.



- Find more ideas 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 centre.

## Healthy eating and keeping active

A healthy, balanced diet and keeping active is good for your general health and lowers your risk of other health problems. There is also some evidence that staying a healthy weight and regular physical activity may slow down the growth of prostate cancer.

If you decide to start treatment in the future, a healthy diet and physical activity can also help with some of the side effects.

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. Your doctor can give you advice and help you get started.



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

## Who can help?

### Your medical team

It could 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.

### Trained counsellors

Many hospitals have counsellors or psychologists who specialise in helping people with cancer – ask your doctor or nurse at the hospital to refer you.

### Hospices

Your local hospice or community palliative care team can provide a range of services including emotional, spiritual, practical and financial advice and support, as well as treatment to manage symptoms such as pain.

### Local support groups

At local support groups, men get together to share their experiences of living with prostate cancer. Some groups have been set up by local health professionals, others by men themselves.

## Prostate Cancer UK services

We have a range of services to help you deal with problems caused by prostate cancer or its treatments:

- **our Specialist Nurses**, who can answer any of your questions in confidence
- **our one-to-one support service**, where you can speak to someone who's been there
- **our online community**, which is a free forum to talk about what's on your mind
- **our fatigue support service**, which is delivered by our Specialist Nurses to help with extreme tiredness.



Speak to our Specialist Nurses on 0800 074 8383 or visit [prostatecanceruk.org/get-support](https://www.prostatecanceruk.org/get-support)

# 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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What other treatments might be 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.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.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

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

### 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 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)**

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

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- Patricia McClurey, Prostate Cancer Specialist Nurse, James Cook University Hospital, Middlesbrough
- Chris Parker, Consultant Clinical Oncologist, Royal Marsden Hospital, Surrey
- Nona Toothill, Urology Clinical Nurse Specialist, Airedale NHS Foundation Trust, West Yorkshire
- Our Specialist Nurses
- Our Volunteers.



**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/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)



**f** Like us on Facebook: **Prostate Cancer UK**

**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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