

Watchful waiting



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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 slightly differently. Use this fact sheet as a general guide and ask your doctor or nurse for more information. You can also chat 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:

 Chat to one of 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 your cancer over the long term, and avoid treatment unless you get symptoms or signs that the cancer is growing.

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

Also, many treatments for prostate cancer, like radiotherapy, surgery or hormone therapy, can cause side effects. These include fatigue (extreme tiredness), and urinary, erection and bowel problems. 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).



PROSTATE CANCER UK

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 names such as 'active monitoring', 'deferred therapy', 'watch and wait' and 'wait and see' to describe both watchful waiting and active surveillance. These 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:

- prostate cancer treatments may not be suitable for you because you have other health conditions or treatment may not help you live longer
- your prostate cancer isn't likely to cause any problems during your lifetime, or shorten your life
- you do not want to have treatment.


It's important that you discuss other treatment options with your doctor, and if you're happy to go onto 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 your options. They can explain your test results and discuss all 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 also have more information about diagnosis and different treatments in our other fact sheets. You can also

 chat to one of our **Specialist Nurses**.



**Before my appointments,
I find it useful to write
down any questions to
ask the doctor.**

A personal experience

What are the advantages and disadvantages of watchful waiting?

What is important to one person may 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 or radiotherapy can help manage them. But many men never need treatment.

Disadvantages

- There is a chance 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. Treatments such as hormone therapy can't cure the cancer, but they can help keep it under control, sometimes for several years.
- You might worry about your cancer growing, and about getting symptoms. But men having treatment often have these worries too.
- Partners, family members or friends might worry and find it hard to understand why you're not having treatment.

What does watchful waiting involve?

If you're on watchful waiting, you may have tests to monitor your cancer and check for any changes. You won't usually have treatment unless you get symptoms.

You'll normally have a prostate specific antigen (PSA) blood test at your GP surgery or hospital clinic around once a year. Each hospital may do

things slightly differently, so ask your doctor or nurse for more information on how often you will have a PSA test.

The PSA blood 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 a digital rectal examination (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 new or different symptoms, then you may be given an appointment with a doctor or nurse. This could be at your GP surgery or 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.

A common treatment to control prostate cancer and help improve symptoms is hormone therapy. This usually 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, such as pain relief drugs and radiotherapy. For example, radiotherapy may be used to improve pain if your prostate cancer has spread to your bones or other areas in your body (advanced prostate cancer).

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

Deciding whether to go on watchful waiting or have treatment can be difficult. 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 or care team, if you would like one. Most doctors or healthcare teams will be happy for you to have one and will refer you to a different doctor.

Making the most of your appointment

There can be a lot of information to take in at your appointments. Your appointments may be in person, by telephone or online. 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.
- Have a notebook and pen to hand, 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 to record your appointment. You could do this using your phone or another recording device. Talk to your doctor or nurse first to make sure they are happy to be recorded. Not everyone is comfortable with being recorded and some hospitals might have policies about recording appointments.

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

Being diagnosed with prostate cancer can change the way you think and feel about life. It's normal to feel scared, worried, stressed, helpless or even angry. 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.

Finding out about things you can do to help yourself can help you to feel more in control. 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 someone with prostate cancer: A guide for partners and family.**

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 to help you understand your treatment options.
- **Talk to someone.** Share what you're thinking – find someone you can talk to. It could be someone close, someone who has had prostate cancer or someone trained to listen, like a counsellor or your doctor or nurse.
- **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.
- **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.**

Visit prostatecanceruk.org/living for more

ideas, or 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

You might find it useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain your diagnosis, listen to your concerns, and put you in touch with other people who can help.

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 if this is available. You can also refer yourself for counselling on the NHS website, or you could see a private counsellor. To find out more, visit www.nhs.uk/counselling or contact the British Association for Counselling & Psychotherapy.

Support groups

People affected by prostate cancer get together to share their experiences of living with it. Some groups also hold meetings online. You can ask questions, share worries and know that someone understands what you're going through. Many also welcome partners, friends and relatives. To find your local support group, please visit www.tackleprostate.org/supportgroups

Hospices

Your local hospice or community palliative care team can help with emotional, spiritual, practical and financial advice and support, as well as treatment to manage symptoms such as pain. Hospices aren't just for people at the end of their life. You can often use their services while living at home.

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 questions or worries 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 place to ask questions or share experiences
- **our fatigue support**, speak to our Specialist Nurses about ways to help manage your fatigue.

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.



Why is watchful waiting suitable for me?

Why can't my prostate cancer be cured?

Are any treatments suitable for me?

What tests will I need, and how often?

What signs and symptoms should I look out for?

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

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

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

Information about cancer and clinical trials.

healthtalk.org

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

Telephone: 0808 808 0000

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

Maggie's

www.maggies.org

Telephone: 0300 123 1801

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

Penny Brohn UK

www.pennybrohn.org.uk

Telephone: 0303 3000 118

Courses and physical, emotional and spiritual support for people with cancer and their loved ones.

Tackle Prostate Cancer

www.tackleprostate.org

Support for people with prostate cancer and their loved ones, including support groups.

About us

We're Prostate Cancer UK. We're striving for a world where no man dies from prostate cancer.

We work to give everyone the power to navigate prostate cancer, by providing up-to-date, unbiased and accurate information about prostate diseases. But we're not here to replace your doctor. Always get advice from a healthcare professional to help you make decisions that are right for you.

References used in this fact sheet are available at prostatecanceruk.org

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

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- Samantha McBeigh, Uro-oncology Clinical Nurse Specialist, Belfast Health and Social Care Trust
- Joanne Sethi, Clinical Nurse Specialist, Imperial College Healthcare NHS 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



Chat to one of our
Specialist Nurses
0800 074 8383*
prostatecanceruk.org

Donate today – help others like you

Every year over 52,000 men get the life-changing news that they have prostate cancer. But thanks to our generous supporters, we're there to help men when they need us most. Whether that's providing unbiased, accurate information that's free to all, just like this fact sheet, or offering a range of other support services like our Specialist Nurses helpline for men and their families.

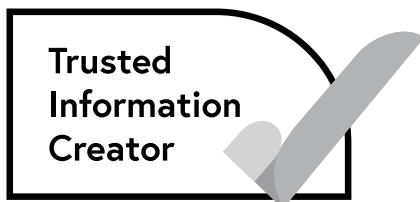
So, did this fact sheet help you? Do you want more men to get support just like this? Your donation can make this happen:

- £10 could fund a call with one of our Specialist Nurses, who support men and those who love them with free, unbiased, confidential help and information.
- £20 could give 40 men vital information about their prostate and their risk of prostate cancer with our handy **Know your prostate: a quick guide**.

To donate, visit prostatecanceruk.org/donate or call **0800 082 1616** or text **PROSTATE** to **70004**[†].

And there are so many other ways to support us too. From running, rowing and facial hair growing, to volunteering and campaigning for change. Head to 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



Patient Information Forum

@Prostate Cancer UK @ProstateUK @ProstateCancerUK

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To be reviewed November 2027

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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