Watchful waiting

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- Making a decision
- What support is available?
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- About us

This fact sheet is for men who would like to know more about watchful waiting. Watchful waiting is a way of monitoring prostate cancer and only having treatment if you develop symptoms. Partners and families of men with prostate cancer may also find this information useful.

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 details about the treatment and help available to you. You can also speak to our Specialist Nurses on our confidential helpline for more information on watchful waiting and other treatments for prostate cancer.

What is watchful waiting?
Watchful waiting is a way of monitoring prostate cancer that is not causing any symptoms or problems. The aim is to monitor the cancer over the long term because prostate cancer is often slow growing and may not cause you any problems or symptoms in your lifetime.

If you choose watchful waiting, you will not start treatment until you get symptoms, such as problems passing urine or bone pain. If your prostate cancer does cause symptoms then you are likely to be offered a type of treatment called hormone therapy to help manage these. See page 2 for more information.

Who can go on watchful waiting?
Watchful waiting may be suitable for you if your prostate cancer is not currently causing you any symptoms or problems, and:
- you have other health conditions so may not be fit enough for treatment such as radiotherapy or surgery, or
- you are an older man and your prostate cancer may not ever cause you any problems in your lifetime or shorten your lifespan.

Treatments for prostate cancer like radiotherapy or surgery (radical prostatectomy) can cause side effects such as problems with erections, problems passing urine and bowel problems. For some men these side effects may be long term and may have a significant impact on their quality of life. If you decide to go on watchful waiting you will avoid the side effects of these treatments.
Unsure about your diagnosis and treatment?
If you have any questions about your diagnosis or treatment ask your doctor or nurse. They will be happy to explain your test results and talk with you about your treatment options. It is important you feel you have enough time and all the information you need before making a decision about treatment. We have more information about diagnosis and treatment in our Tool Kit. You can also speak to a Specialist Nurse on our confidential helpline.

What does watchful waiting involve?
If you decide to go on watchful waiting you will not have any treatment for your prostate cancer. Your doctor or nurse will normally ask your GP to give you a prostate specific antigen (PSA) blood test every four to 12 months. This will give them a good idea about any changes to your prostate cancer. You may also have digital rectal examinations (DREs) and other blood tests and urine tests, although this will vary. Some men may have these tests in the hospital. You will not usually need to have a prostate biopsy, which involves taking small pieces of prostate tissue to look at more closely under a microscope for signs of prostate cancer.

To find out more about these tests you can read our Tool Kit fact sheet, How prostate cancer is diagnosed.

If any changes are picked up on these tests or you have any new or different symptoms then your GP may refer you to see the doctor or nurse at the hospital.

You should let your GP or doctor or nurse at the hospital know if you have any symptoms or changes to your health. Things to look out for include:
- changes to your urinary habits, for example blood in your urine and problems passing urine
- changes to your bowel habits
- new problems with erections
- new aches and pains in your back or bones, or
- new swelling in your legs.

If you start getting any of these symptoms you may need to have some further tests to see if your cancer has spread and you may be offered treatment.

The most common treatment to help improve these symptoms is hormone therapy, as it shrinks the cancer cells, wherever they are in the body. You can read more about this in our Tool Kit fact sheet, Hormone therapy.

What is the difference between watchful waiting and active surveillance?
Watchful waiting and active surveillance are both ways of monitoring prostate cancer and avoiding immediate treatment. However, there are some differences, including:
- who may be suitable for each approach, and
- what kind of tests you will have and how often you will have them.

Active surveillance usually involves more regular hospital tests, such as prostate biopsies. The aim is to treat the cancer quickly if it shows signs of changing and to try and get rid of it completely. Active surveillance is suitable for men with cancer that is contained within the prostate gland (localised prostate cancer), who are likely to be fit enough to have treatment such as surgery or radiotherapy.

Watchful waiting usually involves check-ups at the GP surgery rather than at the hospital. Check-ups usually happen less often than with active surveillance. The aim is to treat the cancer if it starts causing problems or symptoms. Treatment aims to control the cancer rather than getting rid of it completely.

My doctor suggested that he see me yearly. I felt this wasn’t often enough so I asked for six monthly visits for reassurance.
A personal experience
What are the advantages and disadvantages of watchful waiting?

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

**Advantages**
- As watchful waiting does not involve having treatment you will avoid the physical side effects of treatment and you should be able to enjoy your normal life and activities.
- You will not need to have invasive tests such as regular prostate biopsies.
- Some men may never need treatment at all.

**Disadvantages**
- Some men may worry about their cancer changing and the possibility of developing symptoms. Partners and family also often worry about their loved one and find it hard to understand why they are not having treatment.
- There is a chance that the cancer may grow and change more quickly than expected. If this happens you can start treatment such as hormone therapy to control the cancer.

“Having watchful waiting means that I have to trust my consultant and his team to monitor my condition when necessary with PSA tests and occasionally, DRE. I accept that I am in good hands and find that I can forget the problem between hospital visits.”

A personal experience

Making a decision

Your doctor or nurse should discuss with you all the treatment options that are suitable for you. Your age is not the only thing your doctor or nurse will think about when considering whether watchful waiting is right for you. For example you may be an older man, but in good health and feel that you would benefit from treatment. If you would like to discuss treatment but do not feel you have been given this chance, let your doctor or nurse know that you want to discuss it.

You can ask your doctor or nurse for an opinion about your treatment from a different doctor (a second opinion). Although you do not have a legal right to a second opinion, most doctors are happy for you to have one and will refer you to a different doctor.

Your personal feelings and preferences are important. It is not always easy expressing your wishes, especially when making difficult decisions. Some of these suggestions may help:
- Take our booklets and leaflets into your appointment with you. Use them as a way to talk things through with your doctor or nurse.
- Write down any questions you want to ask before your appointment and take them in with you. There are some suggestions at the end of this fact sheet.
- Take someone into the appointments with you, for example a relative or friend.
- Get further advice from the Patient Advice and Liaison Service (PALS) or if you live in Scotland, the Scotland Patients Association. Age UK offer support to older people.
- Speak to one of our Specialist Nurses on our confidential helpline.

What if I change my mind?

If you are having watchful waiting, but want to discuss other options for managing your prostate cancer, contact your GP or your doctor or nurse at the hospital. They should discuss whether there are any other treatments that are suitable for you.
What support is available?
Some men are happy to avoid treatment, but other men may find it difficult and feel worried or anxious. It may help to talk to family or friends about how you are feeling. You could also speak to your doctor or nurse or call our Specialist Nurses on our confidential helpline.

Some people find that it helps to talk to other men with prostate cancer. There are prostate cancer support groups throughout the country. You can find details of your nearest group by calling our helpline, visiting our website or by asking your doctor or nurse.

We can also arrange for one of our trained volunteers with personal experience of prostate cancer to speak to you through our one-to-one support service. Please call the helpline for more information.

If you have access to the internet, you may also like to sign up to Prostate Cancer UK’s online community, where you can share your views and experiences with others affected by prostate cancer. Visit our website prostatecanceruk.org to sign up.

What can I do to help myself?
Your general health
If you have other health problems make sure that these are being treated. You could ask for a review of your medications or a general check-up at your GP surgery.

Diet
We need more research to show clearly how diet can help men who have been diagnosed with prostate cancer. But a healthy diet will benefit your overall health and reduce your risk of medical problems such as heart disease and diabetes. There is some evidence that certain foods may slow down the growth of prostate cancer or reduce the risk of it returning after treatment.

Physical activity
It is not clear whether exercise can help to slow down the growth of prostate cancer. But keeping active is important for your general health and wellbeing and can help you cope with feelings of anxiety or depression.

For more information and tips on healthy eating and physical activity read our Tool Kit fact sheet, Diet, exercise and prostate cancer.

Read our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues, for more information about getting emotional support.

If you are a partner, family member or friend of a man affected by prostate cancer then you may also need some support – all the services mentioned here are also open to you.

I found that my specialist nurse was very reassuring in respect of pointing out the benefits of watchful waiting at any stage of the disease.

A personal experience
Symptoms to look out for
Ask your doctor or nurse to fill in specific symptoms or changes to your health to look out for and who you should contact about them here:

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PSA levels
You may like to use this page to record the results of your PSA tests. If you need more space, you can order PSA record cards by calling Prostate Cancer UK on 0800 074 8383.

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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.

Other than watchful waiting, what treatments would be suitable for me?

Why is watchful waiting suitable for me?

How often will I need to have a PSA test?

Will I need any other tests?

Will I have appointments at the hospital or at my GP surgery?

What signs and symptoms should I look out for?

If I develop any new symptoms who should I contact?

If I need to start treatment, such as hormone therapy, what will this involve?

What else can I do to improve my overall health and wellbeing?
More information

Age UK
www.ageuk.org.uk
0800 169 6565 (8am-7pm, Mon-Fri)
Information or advice for older people on anything from health to housing.

Patient Advice and Liaison Service (PALS)
www.pals.nhs.uk
For information about resolving concerns or problems when you are using the NHS and the NHS complaints procedure. You can find your local PALS office by going online or asking at your local hospital.

Macmillan Cancer Support
www.macmillan.org.uk
Freephone Cancerline: 0808 808 2020 (9am-9pm, Mon-Fri)
For support and information about cancer, including financial advice.

Scotland Patients Association
www.scotlandpatients.com
0141 942 0376 (9.30am-4.30pm, Mon-Fri)
Provide support and information to patients in Scotland. Can advise patients who feel they have received inadequate or inappropriate health care.

About us

Prostate Cancer UK fights to help more men survive prostate cancer and enjoy a better life.

This fact sheet is part of the Tool Kit. You can order more Tool Kit fact sheets, including an A-Z of medical words, which explains some of the words and phrases used in this fact sheet.

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

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• Prostate Cancer UK Volunteers
• Prostate Cancer UK’s Specialist Nurses

Tell us what you think
If you have any comments about our publications, you can email: literature@prostatecanceruk.org
or write to the Information Team at: Prostate Cancer UK
100 Cambridge Grove
London W6 0LE
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. To help us continue providing free information, you could make a donation of any amount. Please call us on 020 8222 7666, visit prostatecanceruk.org/donations 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

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The helpline is open Mon - Fri 10am - 4pm, Wed 7pm - 9pm
*Calls are recorded for training purposes only.
Confidentiality is maintained between callers and Prostate Cancer UK.

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