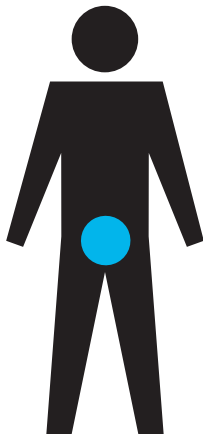


SPOTLIGHT ON

Watchful Waiting to manage prostate cancer



Our aim is to help all those affected by prostate problems whether it is the benign condition BPE (an enlarging prostate), the benign disease prostatitis or prostate cancer. It is anticipated that most of our information will be suitable, relevant and helpful for men, and those born biologically male who still have a prostate. However, there might be times when your health care (such as appointments and treatment(s)) may be slightly different from our information. Our information will not be as applicable for those men born without a prostate. Most of our publications will use the term 'you' but there may be times that we will have to use the terms man, men or male.

It might be helpful if you are comfortable and willing to make your healthcare team aware of your gender identity so that they can provide the most relevant information and appropriate health care for you.

What is the prostate?

Only men (and those born biologically male) have a prostate. It is inside the pelvis, just below the bladder and in front of the back passage. The prostate is usually about the size of a walnut, but it increases in size as you get older. It wraps around the tube that allows urine to flow out of the bladder and for some men semen to pass out through the penis.

What does the prostate do?

It supplies the fluid to protect and nourish sperm during intercourse. Prostate Specific Antigen or PSA is also made in the prostate. Some PSA leaks out into the blood and can be measured. This is called your PSA level.

What is prostate cancer?

Prostate cancer happens when the cells in the prostate grow and multiply more quickly than normal. This causes a growth or tumour. The chance of developing cancerous cells or cancer in the prostate increases as you get older. However, most prostate cancers grow slowly and for some, prostate cancer doesn't have any effect on or shorten their life.

Symptoms that you may have:

- needing to pass urine more often than before and 2 or more times during the night;
- finding it difficult to start passing urine;
- seeing blood in your urine;
- needing to get to the toilet quickly with the risk of getting caught short;
- taking longer to empty your bladder and sometimes feel you can't empty your bladder completely;
- stopping and starting when passing urine.

How do you know I have prostate cancer?

Your urologist, clinical nurse specialist (CNS) or GP may have noticed that:

- Your PSA level is raised over what it should be for your age. Perhaps you have had additional tests/examinations to confirm prostate cancer;
- Your digital rectal examination (DRE) found changes in your prostate such as a hardened area, an odd shape or an unusual lump. If you have previously had bowel surgery the GP, urologist or CNS may not be able to examine your prostate by DRE.
- If you had a scan or biopsy, it showed prostate cancer

Watchful waiting for prostate cancer

Some people with prostate cancer that has not spread won't need treatment straight away – and indeed some may never need treatment.

Your urologist, Clinical Nurse Specialist (CNS) or GP believes that 'Watchful Waiting or Watch and Wait' is most appropriate for you. It means that you won't have any active treatment for your prostate cancer. Instead, your GP or Practice Nurse will keep an eye on you by doing a check-up now and again.

At the check-up they'll ask about your symptoms, any new symptoms that you have noticed and consider your PSA test results. It's a way of keeping an eye on you. Usually you won't have any further/other tests for your prostate cancer, unless the GP, urologist or CNS thinks your cancer may be starting to change or grow.

Over the coming years, your prostate cancer may grow and might eventually spread. Even if the cancer does spread there is still treatment available, although it won't be possible to cure the cancer. Hormone treatment might be started with the aim of dampening down/suppressing the activity of the cancer cells with the expectation that the prostate cancer would not affect your life expectancy. In fact, some people live their full life without ever needing their prostate cancer treated.

Why has watchful waiting been suggested as appropriate for me?

If the urologist, CNS or GP believes that:

- i. You have the type of prostate cancer that grows very slowly, is unlikely to spread and your symptoms don't trouble you too much. This is because prostate cancer has different forms, they're not all the same. Cancerous cells can behave and grow at different rates.
- ii. You have another health condition(s) which means you wouldn't be well enough to have other prostate cancer treatments because of the additional risks to you and the bothersome side-effects that treatment might cause. Instead, your GP, CNS or urologist may concentrate on managing the other illnesses you have that may affect you and your quality of life more than your prostate cancer;
- iii. You are of an age where there is no clear evidence that treating your prostate cancer to try to cure it would bring life expectancy benefits over watchful waiting. The side-effects of treatment may be more troublesome for you.

Living with Watchful Waiting

Knowing that you have prostate cancer that isn't going to be treated may sound quite scary and you'll probably wonder why. Your GP, CNS or urologist will only ever suggest 'watchful waiting' if they think it's best for you and how you are. People on watchful waiting may never need treatment for their prostate cancer or it may be years before they need treatment.

The plus side of being on watchful waiting is that you won't get the side-effects that treatment for prostate cancer may cause (such as erectile dysfunction, incontinence). However, for some not having treatment can be very worrying, causing some stress and anxiety. If you feel very anxious or upset then there are people that you can speak to. You'll find some suggestions of help and who you can speak to at the end of this leaflet.

Who will look after me?

In all probability your GP or Practice Nurse will keep an eye on your prostate cancer by seeing you on a fairly regular basis. Most likely they will do a PSA test and they will certainly ask about symptoms and in particular about any new symptoms that you are having. You may also have check-ups with the hospital team.

How often might I see my GP, practice nurse, CNS or urologist?

Usually, every 6 to 12 months. You may have a PSA test or possibly a DRE. (A physical examination of your prostate). If your GP or practice nurse normally sees you every few months, then don't forget to make your appointment to see them. Prostate Scotland now has the Prostate Scotland Cancer Navigator App available to download. You can mark in appointments, set reminders, keep track of your PSA and any symptoms that you have.

What symptoms should I look out for to let my GP or practice nurse know about?

It's important to let your GP, practice nurse, CNS or urologist know about any change in your symptoms and any new symptoms while your cancer is being looked after/monitored by watchful waiting. You might find it helpful to jot down any new symptoms or questions that you want to ask before you go to your appointment.

Let the GP or Practice Nurse know if you:

- Have any **new** pain, aches or stiffness in the lower back, hips or upper thighs.
- If you have become unable to control peeing or passing motions.
- Have an unexplained weight loss.
- See blood in your urine.
- Have problems when passing urine.
- Have loss of sensation or numbness in your saddle area. (The saddle area is your groin, buttocks, genitals, and the upper inner thighs)

What will happen if it's found my cancer is growing?

Your GP, CNS or urologist may suggest you start hormone therapy. This will be to help control the cancer and ease your symptoms rather than cure the cancer. You may find the Prostate Scotland booklet on Hormone Therapy helpful. It is available on our website at www.prostatescotland.org.uk/resources or you can contact us for a copy.

What can I do to help me cope with my prostate cancer?

1. Talk to the people that you care about and that care about you. Your family and friends can be a great support. As prostate cancer can run in families, if you have sons or brothers, it may be helpful to let them know about your diagnosis so they can speak to their GP about their increased risk.

● WATCHFUL WAITING TO
MANAGE PROSTATE CANCER



There are organisations who provide confidential support to let men talk about what they are going through, for example:

www.prostatescotland.org.uk One-to-One support run in partnership with some Maggie's Centres

www.maggies.org

www.cancersupportscotland.org

Prostate Cancer UK Specialist Nurses tel 0800 074 8383

Macmillan cancer support line call 0808 808 00 00

Cancer research UK, Nurse helpline 0808 800 4040

Here you will find great examples of men sharing their stories. If you don't feel ready to talk about your own experience, it can still be useful to hear other men talk about their experience of prostate cancer, and the videos below allow you to listen without needing to join a group.

www.theinfopool.co.uk/personal-stories

2. There may be a prostate cancer support group in your area that you can go along to. Often these groups have people who are also being looked after by Watchful Waiting and are happy to share their experiences and provide some support. Some of these groups run a 'buddy system' so you can talk to someone who is on Watchful Waiting. You may find the Prostate Scotland website helpful www.prostatescotland.org.uk. For details of support groups, you can search Prostate Scotland Support
3. Would time away and just forgetting about everything help for a wee while? Trying a new hobby that you've thought about doing for a long time but never got round to it?

- Getting back to a hobby or activity that you enjoyed before
- a game of golf, bowls or darts.
- Mending the fence, cutting the grass, putting up the shelf.
- Visiting gardens or historical sites that you've always put off.
- Visiting museums, art galleries, listening to music, trying to paint or sketch, write short stories or poetry, go dancing.
- Trying yoga, meditation, Tai Chi.

There are so many things out there that you might never have tried so give them a go and have fun!

4. For further information about prostate cancer there is a range of information on the Prostate Scotland website www.prostatescotland.org.uk and to see all our resources go to <https://www.prostatescotland.org.uk/resources>. You can also find information about the support services that we provide in partnership with Maggie's which include One -to Support **www.prostatescotland.org.uk/help-and-support-for-you/cancer-support-specialist** in several parts of the country as well as Living Well with Prostate Cancer courses. See page 13 for more information.
5. Maggie's Centres can also provide support for you, your wife/spouse, partner or family.
6. If you are feeling very unhappy, worried, anxious or just 'down in the dumps' then speak with your GP. He/she may be able to refer you to a counselling service for some help and support. There are also support organisations such Maggie's Centres.

● WATCHFUL WAITING TO MANAGE PROSTATE CANCER

7. Everyone can have a bad day and it may be difficult to stay positive all the time, that's quite normal. Try not to worry too much and take each day as it comes.
8. Look after yourself. It's all too easy to fall into the trap of thinking about your diagnosis so much that you forget to look after you. Try to have a good diet with plenty of fresh fruit and vegetables. Sleep is important too. Talk to your CNS, Urologist, Oncologist or GP if you're having trouble sleeping.

Look out for our 'Living well with prostate cancer' 6-week course run in partnership with some Maggie's Centres. www.prostatescotland.org.uk/help-and-support-for-you/living-well-with-prostate-cancer-course

Exercise is important for all those diagnosed with prostate cancer and in particular for those on hormone therapy. In some areas of Scotland, we have a specially designed 12-week exercise programme for men diagnosed with prostate cancer to participate in. In addition, the course builds your knowledge on diet, nutrition and healthier lifestyles.

We have run several programmes in 2023 which were so successful that other football clubs are now offering the Prostate FFIT (Football Fans in Training) 12-week programme. For more details and to find out if there will be a course near you, please go to our website <https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit>

This website is well a worth a look as it is dedicated to giving support at every stage of your journey. They offer a range of workshops and classes providing advice and guidance around the physical changes you may experience while undergoing treatment.

lookgoodfeelbetter.co.uk/support/men/
<https://lookgoodfeelbetter.co.uk/workshops/>

9. Talk to your GP or CNS if you have any questions.

10. For general information on cancer and support, you can search NHS Inform or use this link www.nhsinform.scot/illnesses-and-conditions/cancer

LOOK AFTER YOURSELF.

Tips for a healthy diet.

- Having 3 smaller meals a day – breakfast, lunch and dinner. If you're hungry between meals then try a small snack of some fresh fruit, granola bar, oatcake, small plain biscuit, yogurt, popcorn, small pancake or small portion of nuts.
- Don't have red meat as often each week – switch to chicken or fish. Have fish at least twice a week and include the oily fish like salmon, herring, kippers, sardines or mackerel.
- Have at least 5 portions of vegetables or fruit each day whether these are fresh, frozen, tinned or dried fruit.
- Switch from refined cereals like white bread to wholemeal bread and wholegrain breakfast cereal.
- Have 6-8 glasses of fluid each day.

If you are overweight then cut out or cut down on sugar, sweets, chocolate, cakes, biscuits, sugary drinks, fried food and take-aways.

Smoking

Stop smoking. If you need help to stop, call 0800 848484 to find out more.

Alcohol

Unless you've been told not to drink alcohol, it's best keep alcohol within the sensible drinking guidelines. For more information go to **www.drinkaware.co.uk**

Some people may be tempted to try and escape it all by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make how you're feeling worse and might affect any treatment that you are on.

Exercise

Recent studies have all pointed to the benefit of taking regular exercise. Aim for at least 30 minutes of moderate exercise every day, at least 5 times a week. Moderate exercise can include going for a brisk walk, swimming, mowing the lawn, doing the gardening or washing and polishing the car. This may help with your general health and feeling of wellbeing and may help if you need to lose some weight.

On our website are 2 excellent special exercise videos for men with prostate cancer. **www.prostatescotland.org.uk/help-and-support-for-you/exercise-video**

If you haven't exercised for a long time then you will need to build this up gradually and always check with your GP, practice nurse, CNS or urologist before starting to exercise or use our exercise videos.

There is further information and tips for a healthy lifestyle to be found in the leaflet Prostate health 'A guide to healthier lifestyle choices'. This can be found at the **www.prostatescotland.org.uk/resources** or can be ordered from the address at the back of the booklet.

You may find the Prostate Scotland website helpful **www.prostatescotland.org.uk**. For details of support groups you can search Prostate Scotland Support Groups.

For general information on cancer and support, you can search NHS Inform Cancer Services Directory.

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Prostate Scotland is developing a range of support and wellbeing services to help people across Scotland navigate prostate cancer. It's called our COMPASS project and in time it will cover information, courses, exercise programmes, workshops and support services for people with prostate cancer and disease. Visit www.prostatescotland.org.uk/help-and-support-for-you to see what's available.

We currently offer:

- Prostate Scotland Cancer Navigator App available and free to download from the Apple Store or Google play. This includes information on treatment decision making, the ability to record your consultation (with permission), appointment and medication diaries, monitor side-effects and much more.
- The opportunity to speak to a Cancer Support Specialist through a joint initiative with Maggie's in some areas of Scotland. The Cancer Support Specialists have expert knowledge of prostate cancer, and you can speak to them face-to-face at a Maggie's centre, on the phone or by video call. Whether it's talking through being diagnosed with prostate cancer, chatting about your treatment options, speaking about your symptoms and side-effects or the impact it's had on your life, this service can help.
- A 'Living Well with Prostate Cancer' This is a 6 week course for those undergoing treatment or when treatment has finished. We take a look at fatigue, urinary problems, side-effects and how to minimise them, erectile dysfunction and relationships, eating well and the practicalities of living with prostate cancer.

- Our special online exercise programmes for those living with prostate cancer are particularly relevant for those on hormone therapy. Please check with your CNS, oncologist, urologist or GP that these programmes are suitable for you before starting to exercise. Available on our website **www.prostatescotland.org.uk/help-and-support-for-you/exercise-video**
- In some areas of Scotland, we have a 12 week programme for men diagnosed with prostate cancer to participate in a specially designed exercise course, as well as building your knowledge on diet and nutrition and healthier lifestyles. You can check if there is course running near you through the link given below.'

For more information visit

prostatescotland.org.uk/help-and-support-for-you

● WATCHFUL WAITING TO MANAGE PROSTATE CANCER

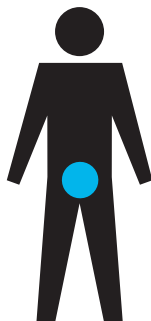
Our work:

All our awareness materials, introductory guides, explanatory guides and 'Spotlight on' guides such as this booklet are available free of charge to individuals and their families and all healthcare settings.

If you found the booklet helpful, you can help us reach many more people with awareness, information and support about prostate disease and prostate cancer by doing the following:

- Obtaining and wearing a Prostate Scotland badge
- Volunteering some of your time
- Taking part in or organising a fundraising event or making a donation.





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**Prostate
Scotland was
awarded Health
Charity of the Year
2017 in the Scottish
Charity Champions
Awards.**

