

Trans women Your guide to the prostate, prostate disease and prostate cancer.

inform • support • advance
www.prostatescotland.org.uk

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Most prostate cancers grow slowly so if you have any concerns or worrying symptoms, then the earlier you see your GP and a diagnosis is made the better. If prostate cancer is found when it is still within the prostate there are treatments available to potentially cure prostate cancer. Even if it has spread to other areas in the body there are many treatments aimed at controlling and slowing down the growth of these prostate cancers.

The risk of getting prostate cancer may be slightly lower if you've had gender affirming therapy **but it can still happen.**

Symptoms to look out for

The symptoms of prostate issues are most likely be similar to those experienced by cis-gender men. However, if you experience any, it is best to ask for advice from your GP, urologist or the surgeon as these symptoms may not be caused by a prostate problem.

Having to pee more often than usual
Getting up to pee 2 or more times during the night
Waiting for a while before urine starts to flow then straining to keep going
Having to get to the toilet fast with the risk of getting 'caught short'
Taking longer to empty your bladder than usual
Stopping and starting when peeing
Having some pain or burning feeling when peeing
Seeing blood in urine
After finishing, a bit more urine trickling out with no control over this

Having these symptoms does not necessarily mean you have prostate cancer or disease.

It is very important to note that sometimes with early prostate cancer which is still retained within the prostate, there may not be any symptoms at all.

About this leaflet

This leaflet is for trans women (women who were assigned male at birth (AMAB) and anyone who may support them. It is also relevant for trans or non-binary people who do not identify as women, but who were assigned male at birth. So far, there hasn't been much research undertaken on diagnosis and treatment of prostate disease and prostate cancer in trans women. This leaflet is based on the studies that have been published and will be updated as and when new information becomes available. Thanks to LGBT Health and Wellbeing for their help in compiling this leaflet. www.lgbthealth.org.uk

What is gender affirming treatment?

Some trans people undergo gender affirming medical treatment, including hormone replacement therapy (HRT). For some trans women, HRT can include taking anti-androgens. These block the production of androgen hormones, such as testosterone. As prostate cancer is fuelled by testosterone, blocking testosterone may lower overall risk of developing prostate cancer. Most trans women will continue taking HRT for the rest of their lives.

Why are trans women at risk of prostate disease and prostate cancer?

As trans women still have a prostate they can develop prostate disease and prostate cancer.

What is the prostate?

It starts out about the size of a pea at birth, and slowly grows to about the size of a walnut when a person is in their 20s. After the age of 40, it begins to grow again, which can cause problems when passing urine. The prostate supplies the fluid that mixes with sperm to form semen. Prostate Specific Antigen (PSA) is made in the prostate.

The prostate is inside the pelvis, just below the bladder. It usually sits in front of the back passage. The urethra (waterpipe) which takes urine out of the body runs down through the middle of the prostate. If a trans woman has had surgery to form a vagina, then this will most likely be positioned between the prostate and back passage.

Tests that you might be asked to have in your GP Practice.

The GP may:

- Ask about symptoms, especially about difficulties in passing urine.
- Ask if anyone in your family has/had prostate cancer.
- Test your urine for any signs of infection or glucose (a type of sugar).
- Take some blood tests to check your kidneys are working properly.
- Talk to you about a PSA blood test.

Physical examination of the prostate

Your GP may do a physical examination of your prostate. This is to check the condition of the prostate - the shape, size, any unusual lumps or for any area that feels hard. If you are a trans woman with a vagina the doctor will gently slide a gloved finger into your vagina to feel/examine the prostate through the vaginal wall.

If you have not had surgery to form a vagina, then the doctor will gently slide a gloved finger into your rectum (back passage) to feel the prostate through the bowel wall.

Whether you have a vaginal or rectal examination, the examination might feel a wee bit uncomfortable, but it shouldn't feel painful and only takes around 30 seconds to do. You can ask for someone (like a friend, family member, or partner) to be with you when you are having the examination, and you can request a female doctor if this would make you feel more at ease.

Depending on the results of the PSA test and physical examination, if the GP has any concerns about your results they will refer you to a urologist in hospital.

Tests that you might have if you are referred to a urologist in hospital

MRI scan. (Magnetic Resonance Imaging) or mpMRI scan (multiparametric MRI scan)

You may have an MRI or mpMRI scan in a few weeks. This scan produces detailed pictures of your prostate, and surrounding areas, and can be used to target any suspicious areas if you are advised to have a prostate biopsy.

What is PSA

PSA is made in the prostate, and some can leak out of the prostate into blood. When something is going wrong with the prostate more PSA can leak out giving a raised PSA level. A small sample of blood can be taken from the arm to measure your PSA level.

Your GP should be made aware that PSA results for trans women **will be different** from that of cisgender men. The PSA cut off level for concern and referral for further investigation of prostate cancer, will be lower because of hormone therapy. The usual 'normal' range levels for PSA does not apply for trans women.

What can go wrong with the prostate?

These issues can affect anyone with a prostate, including cisgender men (men who were assigned male at birth) and trans women or other trans people who were assigned male at birth:

BPE or an enlarged prostate. The prostate naturally grows or enlarges as you get older and so can squeeze the urethra. This can result in problems passing urine and the bladder not being able to store as much urine as before.

There are a range of treatments to help with the symptoms of an enlarged prostate.

BPE may be less likely to happen if you've had gender affirming therapy

Prostatitis is often described as inflammation of the prostate, but bacterial infections (germs) can also cause prostatitis.

It can cause urinary symptoms as well as pain in the lower stomach and areas around the prostate. The pain can be quite severe and can affect your quality of life from work to social activities. If you cannot pass urine at all this needs to be treated straight away. Your GP or urologist will decide the best way to treat prostatitis with an individual treatment plan.

Prostate cancer occurs when the cells in the prostate multiply and grow faster than normal causing a growth or tumour.

Prostate biopsy

This usually involves having a local anaesthetic then a very fine needle taking several very small samples of tissue from your prostate and looking at these under a microscope for any signs of prostate cancer. There are different ways of getting these samples from your prostate depending on your circumstances and what showed up on your MRI scan.

The urologist will decide whether you will have:

- A trans-perineal biopsy where a very fine needle will go through the perineum (the area of skin between the scrotum and back passage or the vagina and back passage if you've had gender affirming surgery).
- A transrectal biopsy where a very fine needle will go through the bowel wall to take tissue samples from the prostate.
- If you have a vagina, the tissue sample can be taken through the vaginal wall.

What happens after these tests?

You should get the results of the MRI scan and biopsy in a few weeks' time. If you are diagnosed with prostate cancer, you will have an appointment with the urologist and oncologist to discuss your results and possible treatment(s).

What are the risk factors for prostate cancer?

It is probably best to discuss risk factors for prostate cancer with your GP or your surgeon. Although more research is needed, it seems likely that the risk factors that affect cisgender men may affect trans women, so it's wise to bear these in mind and talk to your GP about any concerns.

Risk factors reported in cis men are:

Age. Age is the main risk factor for prostate cancer. Prostate cancer is uncommon below 50 but it can happen. It becomes more common as you get older.

Family history. Prostate cancer can run in families. If a dad, grandad or brother has been diagnosed with prostate cancer then there is a greater risk of you developing prostate cancer.

If a close female blood relative has been diagnosed with a specific type of breast cancer with the gene alteration BRCA1 or 2, then you may be more at risk of developing prostate cancer.

Background.

Those from a Black or African Caribbean background are more at risk of developing prostate cancer.

Why might prostate cancer/prostate disease not be diagnosed/ or identified in transgender women?

- Trans women and some health professionals NOT knowing trans women (on gender affirming hormones and/or post gender affirming surgery) still have a prostate and that transwomen still are at a risk of developing prostate cancer/prostate disease.
- Lack of awareness about the need for PSA tests.
- Not being aware that PSA results for trans women **will be different**. The PSA cut off level for concern and referral for further investigation of prostate cancer, will be lower because of hormone therapy. The usual 'normal' range levels for PSA does not apply for trans women.
- Trans women not being aware of risk factors of prostate cancer - age, family history, background.
- Trans women being concerned about speaking with health care professionals about their symptoms.

Screening for prostate cancer

At the time of writing there is not a screening programme for prostate cancer in the UK. Instead, GPs are provided with guidance through the Prostate Cancer Risk Management pack which considers the PSA test.

The PSA test checks the level of PSA in the blood. It is the best test there is at the moment to check for something going wrong with the prostate.

There's more information on PSA in our PSA leaflet.



If you have been prescribed hormone therapy to lower the testosterone level, female hormones like progesterone or oestrogen or have had the testes removed then these will have an impact on your PSA level. It will most likely mean that your **PSA levels will be lower than the normal levels for cis men**.

About your CHI number

Your CHI number is your unique health service number. It is a 10 digit number made up with your date of birth (ddmmyyyy), 2 other digits. The 9th number always shows an even number for female and an odd number for male.

When being considered for screening, it is this 9th digit which decides which screening services you will be called for.

Changing your CHI number

If you prefer to change your CHI number as you go through transition.

There is more information if you scan the QR Code



What might you be called for?

Bowel screening.

Everyone between 50 and 74 is automatically sent a bowel screening kit.

Breast screening.

As a trans woman, if you have developed breast tissue you may be at risk of breast cancer.

Abdominal aortic aneurysm (AAA).

This looks for aneurysms (bulges in blood vessels).

Cervical screening.

You don't need to attend as you don't have a cervix.

Helpful references for further information

(Please note that Prostate Scotland is not responsible for the content of any external websites)

Scottish Trans Useful organisations



Scottish Trans Guides



Scottish Transgender Group Links



NHS Inform



Out With Prostate Cancer



LGBT Walnut



Gender Identity Research & Education Society



Screening continued

If you are attending your GP to discuss symptoms and risk factors for prostate disease and prostate cancer, you can ask what the recommended cut off level for PSA is, and when you might be referred for further tests and investigations.

Treatment for prostate cancer

If you are diagnosed with prostate cancer, your treatment will be based on your age, general health, if you have any other medical conditions, your PSA level, the stage of your cancer and whether the side-effects of treatment would have a greater impact on your quality of life than the effect of the cancer.

In general, there is no clear-cut answer on the best way to treat prostate cancer and so far, there hasn't been much research done on treating trans women diagnosed with prostate cancer.

You may be given some options for treatment. Each treatment will be carefully explained to you along with the side-effects of that treatment. Depending on your individual circumstances, grade and stage of your cancer you may be offered treatment to potentially cure prostate cancer while other treatments aim to control the spread of the cancer.

Your urologist and multidisciplinary team which usually includes an oncologist, clinical specialist nurses, specialist physiotherapist and perhaps with input from your gender affirming surgeon will also take into account if you are having or have had gender affirming hormone therapy and gender affirming surgery.

You may be given some options for treatment. Each treatment will be carefully explained to you along with the side-effects of that treatment.

The urologist, oncologist and perhaps your gender affirming surgeon will talk to you about the type of treatment most suitable for your individual circumstances.

Some healthy lifestyle changes to consider

Diet

Try to have a healthy diet low in saturated fat. Reduce the number of times you eat red meat in the week, especially processed meats. Instead, choose chicken and fish. Have at least 5 portions of fruit and vegetables every day. Although not conclusive, many studies have shown that natural substances in plant foods, called antioxidants, may help reduce the risk of developing certain kinds of cancer including prostate cancer.

If you've been told you are overweight by a medical professional, it is important to address this safely. Ask your GP/surgeon for referral to an NHS weight loss clinic.

Exercise

Recent studies have pointed to the benefit of taking regular exercise. Aim for about 30 minutes of moderate exercise, 5 times a week. Moderate exercise can include going for a brisk walk, swimming, mowing the lawn, washing and polishing the car. Taking exercise may help with your general health and wellbeing. If you haven't exercised for a long time, build this up gradually and check with your GP before starting.

For more information: **LEAP**



Smoking

Smoking can affect your health in many ways, so the best advice is to give up. Giving up smoking can be difficult, and it may be worth discussing this with your GP, pharmacist or local smoking cessation advisor.

For more information: **Quit Your Way Scotland**



Alcohol

As long as you've not been told to avoid alcohol, it's best to keep alcohol intake to a moderate amount and within sensible drinking limits. Try to have a couple of 'alcohol free' days each week.

Treatment options might include:

Active surveillance – to carefully monitor the cancer. Treatment is postponed until such times that radical treatment becomes necessary.

Radical prostatectomy – removes the prostate and the small part of the urethra inside the prostate and so, the cancer inside it.

External beam radiotherapy – High energy x-ray beams from outside the body accurately pinpoint the cancer cells in the prostate and destroy them. This treatment is given over a period of days/weeks.

Brachytherapy – tiny metal seeds that emit radiation are placed into the prostate to kill the cancer cells.

Chemotherapy – may be given if the cancer has escaped outside the prostate.

With all the radical treatments aimed at potentially curing prostate cancer there will be side-effects from these treatments. You can discuss these with your health care team.

Making health care staff aware of your gender identity

If you feel comfortable doing so, it is helpful to make your healthcare team aware of your gender identity and any gender affirming care you have undergone or are undergoing so that they can provide the most relevant information and appropriate health care for you.

You can ask healthcare staff to have this conversation in private, and discuss with them how this is recorded, and which other staff will be made aware of this.

Your medical records and the Community Health Index Number, CHI number, may show the sex you were assigned at birth but may not show your gender identity. Letting health care professionals and staff know your chosen name and pronouns can help prevent mistakes by misgendering. If it happens then let staff know so they can avoid the same mistake in future, perhaps discussing how your medical records might be amended.

For more information on sensible drinking limits go to www.drinkaware.co.uk



Helpful sections include 'Understanding unit guidelines', 'Should you take a break from alcohol' and 'How much alcohol is too much'.

Prostate Scotland information booklets

You may find the following booklets helpful:

- Prostatitis Explained.
- BPE and treatments Explained.
- Early prostate cancer Explained.
- Advanced prostate cancer Explained.
- PSA – Get the knowledge



Prostate Scotland Support Services (COMPASS)

Our new support service for those diagnosed with prostate cancer.



Prostate Scotland Cancer Navigator App

<https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-scotland-cancer-navigator-app>



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