MACMILLAN CANCER SUPPORT

Having tests for prostate cancer

About this leaflet

This leaflet is for anyone who may be having tests for prostate cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.

Tests for prostate cancer can be divided into 2 groups:

- Diagnostic tests are done to find out if you have prostate cancer.
- Staging tests are done if you have been diagnosed with prostate cancer.

We cannot advise you about healthcare decisions. You should talk to your doctor, who knows your medical history.

How to use this leaflet

This leaflet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the leaflet. You can always come back to them when you feel ready. On pages 52 to 59, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this leaflet, we have included quotes from people who have had prostate cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

We have other booklets for people who have been diagnosed with prostate cancer and already know what stage their cancer is:

- Understanding early (localised) prostate cancer
- Understanding locally advanced prostate cancer
- Understanding advanced (metastatic) prostate cancer.

You may also find our information on the PSA test helpful. This can be found on our website at macmillan.org.uk/cancer-information-and-support/diagnostic-tests/psa-test

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

We have some information in different languages and formats, including audio, easy read, Braille, large print, interactive PDFs and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00.

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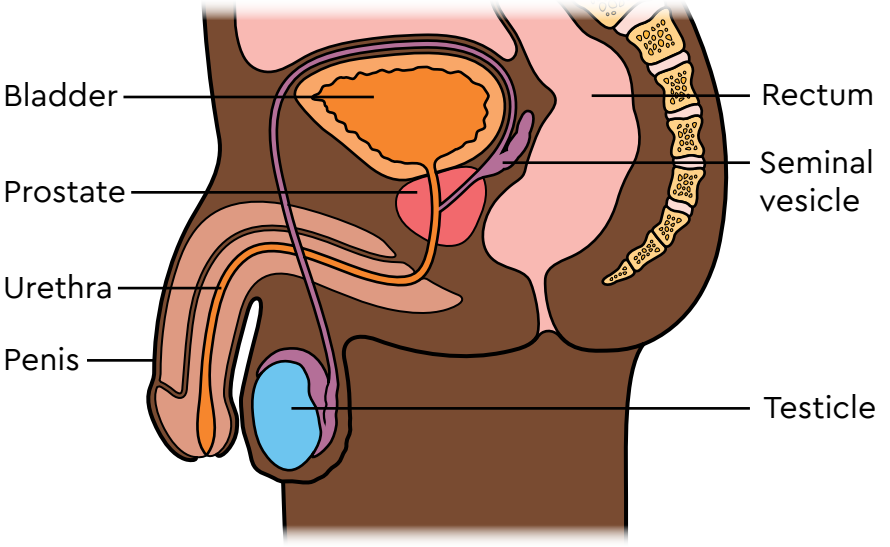
The prostate

The prostate is a small gland about the size of a walnut. It is divided into 2 lobes and surrounded by an outer layer called the capsule. The prostate gets bigger as you get older.

The prostate is below the bladder, surrounding the first part of a tube called the urethra. The urethra carries urine (pee) from the bladder to the penis. The urethra also carries semen, which is the fluid that carries sperm. Just behind the prostate is the back passage (rectum). There are also lymph nodes near the prostate. These are sometimes called lymph glands.

The prostate contains muscle tissue and glandular tissue. Glandular tissue makes and releases substances in the body.

The prostate



What does the prostate do?

The prostate produces a fluid that mixes with sperm from the testicles to make semen. This fluid is stored in 2 tube-shaped glands called the seminal vesicles. These are positioned just behind the bladder. During sex, the muscle tissue helps force (ejaculate) prostate fluid and sperm into the urethra.

The sex hormone testosterone controls how the prostate works. Testosterone is mainly made by the testicles. It is responsible for things like your sex drive, getting an erection and muscle development.

The prostate also makes a protein called prostate-specific antigen (PSA). This helps make semen more watery. Some PSA leaks into the blood and can be measured in a blood test. This is called a PSA test. Doctors use it to help diagnose different prostate problems, including prostate cancer.

If you are a trans woman

People who have a prostate include men, trans (transgender) women and people assigned male at birth. If you are a trans woman and have had genital gender affirming surgery as part of your transition, you will still have a prostate. It is important to talk to your GP or nurse if you are worried about prostate cancer or have symptoms.

We have more information about prostate cancer risk, symptoms, and what to expect from your healthcare team on our website:

- macmillan.org.uk/trans-and-non-binary
- macmillan.org.uk/prostate-cancer

Prostate cancer

Prostate cancer is the most common cancer in men in the UK. About 55,100 people are diagnosed with it each year. It is more common over the age of 65. Although it can happen at a younger age, it is uncommon under the age of 50.

There is a higher risk of getting prostate cancer at a younger age if you are Black or have a strong family history of prostate cancer.

If you are a trans (transgender) woman or are non-binary assigned male at birth, you still need to be aware of prostate cancer. Trans women can develop prostate cancer, but there is not enough evidence to know how common this is.

Prostate Cancer UK has detailed information about trans women and prostate cancer.

The LGBT Foundation can also give you confidential advice and support. OUTpatients is a charity that supports LGBTQ+ people who have been diagnosed with cancer.

Symptoms of prostate cancer

Prostate cancer often grows slowly. Symptoms may not develop for many years. Early prostate cancer may not cause any symptoms.

Symptoms usually happen when the cancer is large enough to press on the tube you pee (pass urine) through. This is called the urethra. The prostate can also become enlarged due to a condition called benign prostatic hyperplasia (BPH). Benign means non-cancerous. BPH can develop as you get older.

The symptoms of benign prostate conditions and prostate cancer are similar. Some people will have both BPH and prostate cancer. If you have any of these symptoms, it is important to have them checked by your GP:

- needing to pee more often than usual, especially at night
- difficulty peeing – for example, a weak flow or having to strain to start peeing
- feeling like you have not completely emptied your bladder
- an urgent need to pee
- blood in your urine
- blood in your semen
- pain when peeing or ejaculating – this is rare.

Sometimes blood in the urine cannot be seen. It can only be detected by a urine test.

Sometimes prostate cancer can cause other symptoms, such as problems getting or keeping an erection (erectile dysfunction). It can also cause loss of appetite and weight loss.

When prostate cancer spreads, it usually goes to the bones. This may cause pain in the bones, such as in the back.

It is important to tell your GP if you have any of these symptoms.

We have more information about the symptoms of prostate cancer when it has spread to other parts of the body. This is called advanced (metastatic) prostate cancer. You can find out more about the symptoms of advanced prostate cancer on our website. Visit macmillan.org.uk/advanced-prostate-cancer

We also have information in our booklet Understanding advanced (metastatic) prostate cancer.

Tests and scans for prostate cancer

If you have symptoms that may be caused by prostate cancer, you usually begin by talking to your GP or practice nurse. They will ask about your symptoms and your general health. They may also ask you about any family history of cancer.

Your GP may do some tests such as a digital rectal examination (DRE) and a PSA test. Depending on the information you give to your GP and the results of these tests, your GP may refer you to a specialist doctor (urologist) at the hospital. Your GP uses national guidelines to help them decide if an urgent referral is needed.

"I had to go to the toilet more often, and I had noticed that when urinating, the stream wasn't as powerful anymore. It was my mum who said that maybe I should go and get checked."

Sean, diagnosed with prostate cancer

Digital rectal examination (DRE)

During a digital rectal examination (DRE), the doctor lubricates a gloved finger with gel. Then they gently insert it through the anus and into the rectum to feel the prostate. As the rectum sits behind the prostate, your doctor can feel for any abnormalities. DRE can detect other conditions, such as inflammation of the prostate (prostatitis) and BPH, as well as a possible prostate cancer.

DRE may feel uncomfortable, but it is quick and should not be painful. Tell the doctor or nurse if you feel pain.

If you are worried or feel uncomfortable about having a DRE, tell your GP or urologist. There are other tests for prostate cancer so they may decide not to do a DRE if you feel this way.

Before a DRE, your GP or practice nurse will explain the test and give you time to get into the right position. You will be asked to lay on a couch, on your side facing away from the doctor, with your trousers and underwear lowered. You will bring your knees up towards your chest. Tell the doctor or nurse if you find this difficult.

Normally the prostate feels smooth. It is common as you get older to have an enlarged prostate. This is known as benign prostatic hyperplasia (BPH). BPH is not cancer. If you have BPH, the prostate is usually enlarged, firm and smooth.

If there is cancer in the prostate, it can feel hard, rough or bumpy. But it can feel normal, even if there are cancer cells inside. It might depend on the size of the cancer and its location in the prostate.

PSA test

The PSA test is a blood test. It can be used with other tests to help diagnose prostate cancer.

Prostate-specific antigen (PSA) is a protein made in the prostate. Some PSA leaks into the blood and can be measured in the PSA test.

Prostate cancer often causes a raised level of PSA. But the test is not always reliable. A raised level of PSA does not mean you have prostate cancer. Naturally, as you get older, the level of PSA in the blood slowly rises. Your doctor can tell you what they think the normal level of PSA should be for you.

The level of PSA in the blood can also be raised for a short time by:

- urine infections or an infection of the prostate (prostatitis)
- recent ejaculation (within the last 48 hours)
- having a tube in your bladder to drain pee (urinary catheter)
- a recent prostate biopsy
- prostate or bladder surgery
- exercising energetically 48 hours before the test – some doctors include cycling in this advice
- receiving anal sex or prostate stimulation during sex – it is best to avoid this for one week before a PSA test.

Some medicines, such as medicines used to treat BPH, can also change the result of your PSA test. Before having a PSA test, tell your GP or nurse about all medicines and supplements you take. This includes ones prescribed for you, ones you buy over the counter, complementary therapies and drugs made from herb and plant extracts.

Your GP will talk to you about meeting with a specialist doctor if:

- your PSA level is raised
- your prostate feels abnormal.

Your GP will ask the specialist to meet with you quickly. Your GP or nurse will give you information about having an urgent referral.

"I had a blood test and the PSA level was high. Then I had a biopsy and an MRI scan, and discovered that I had prostate cancer."

Dougie, diagnosed with prostate cancer

At the hospital

At the hospital, you will meet with a urologist or a urology specialist nurse. The urologist may want to do another PSA test or digital rectal examination.

They will ask about your symptoms, your medications and any other medical conditions you have. They will ask questions to find out whether you have any risk factors for prostate cancer.

After this, they will talk to you about having further tests such as a multi-parametric MRI scan.

We have more information about risk factors on our website. Visit macmillan.org.uk/prostate-cancer

Multi-parametric MRI scan (mpMRI)

An MRI scan uses magnetic fields to build up a detailed picture of certain areas of the body.

A multi-parametric MRI (mpMRI) scan is a specialised type of MRI scan. It gives a more detailed picture of the prostate and surrounding area than a standard MRI scan. Your doctor might recommend you have a mpMRI scan if they think you could have prostate cancer.

The scan results give the doctor more information about whether there are suspicious areas that may be cancer. They give the images of your prostate a score from 1 to 5. Doctors call this the Likert score.

If your Likert score is 3 or more, they will usually offer you a biopsy. The mpMRI scan images help the doctor target the suspicious area of the prostate for the biopsy.

If your score is under 3, you will not usually need a biopsy. Your doctor may talk to you about continuing to monitor your PSA levels. Some slow growing cancers may not show up on an mpMRI scan.

We have more information about having a biopsy on our website. Visit macmillan.org.uk/biopsy

Having the mpMRI scan

The scanner is a powerful magnet. You are asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. Tell your doctor or radiographer if you have ever worked with metal or in the metal industry. Very tiny fragments of metal can sometimes lodge in the body. If you have any metal in your body, you will not usually be able to have an mpMRI scan. But if your doctor or radiographer thinks it is safe for you, they may do the scans but take extra precautions.

Before the scan, you may have an injection of dye into a vein in your arm. This is called a contrast medium. It helps the images from the scan to show up more clearly.

During the test, you lie very still on a couch inside a long tube for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear and speak to the person operating the scanner.

Prostate biopsy

If your test results show that you may have cancer, your doctor may advise you to have a biopsy. This involves a doctor removing samples of prostate tissue with a fine needle. A pathologist is a doctor who is an expert in studying cells. They look at the samples under the microscope to check for cancer.

Before the biopsy, your doctor will talk with you about the benefits and disadvantages and explain possible risks, such as infection. You will usually be given information to take away and read. It is important you have all the information you need to decide about having the biopsy before you agree (give consent).

We have more information about talking to your healthcare team and asking questions on our website at macmillan.org.uk/talk-healthcare-team

The biopsy might take samples from a specific part of the prostate (targeted biopsy) or from different areas of the prostate (template biopsy). Your doctor or nurse will explain the type of biopsy you will have and the possible side effects and risks.

A prostate biopsy is usually done as an outpatient. But sometimes people go into hospital and have the biopsy under a general anaesthetic, which means they are not awake when they have it. Or they may have a spinal anaesthetic, which is an injection of anaesthetic around the spine. This numbs them from the waist down to have the biopsy.

You can usually go home the same day, but if you had a general or spinal anaesthetic, you may stay in hospital overnight. You may have a tube to drain your pee (urine) while you recover. This is called a catheter. It will come out the same day or the next morning.

It is important to drink plenty of fluids after the test. The nurses can tell you how much to drink, and for how long.

To reduce the risk of an infection, your doctor or nurse may give you antibiotics before the biopsy and when you go home.

Transperineal (TP) biopsy

During a TP biopsy, samples of the prostate are taken through the perineum. This is the area between the scrotum and the back passage (anus).

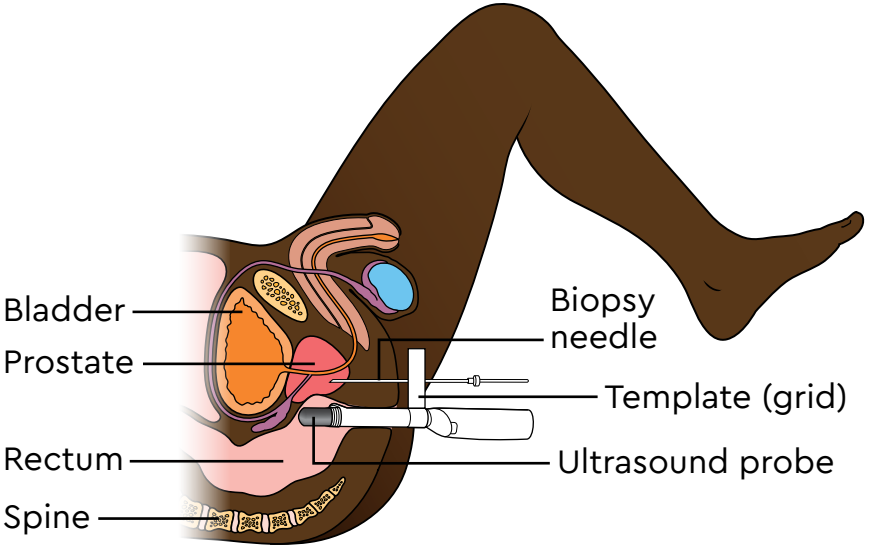
To have a TP biopsy, you lie on your back and the nurses place your legs in special supports (stirrups) to help the doctor reach the prostate. The doctor may place tape over your scrotum to move it out of the way for the procedure. They will do a digital rectal examination before they gently pass a small ultrasound probe into the rectum using lubricating gel. This shows an image of the prostate on a screen. The images from your MRI scan may also be used.

The doctor uses an antiseptic liquid to clean your perineum and then injects the area with local anaesthetic. This helps reduce any pain or discomfort. A special grid is placed on the perineum. This is called the template. The doctor then passes a needle through the grid into the skin of the perineum.

The doctor can take many small tissue samples from different areas of the prostate using the ultrasound scan and results of your MRI scan (template biopsy). They may take samples from a specific area of the prostate (targeted biopsy) or from the whole prostate. The number of samples taken will depend on your PSA, the size of your prostate and mpMRI scan results.

After the biopsy, the doctor places a dressing over the perineum. A TP biopsy usually takes around 30 to 45 minutes.

Having a TP biopsy



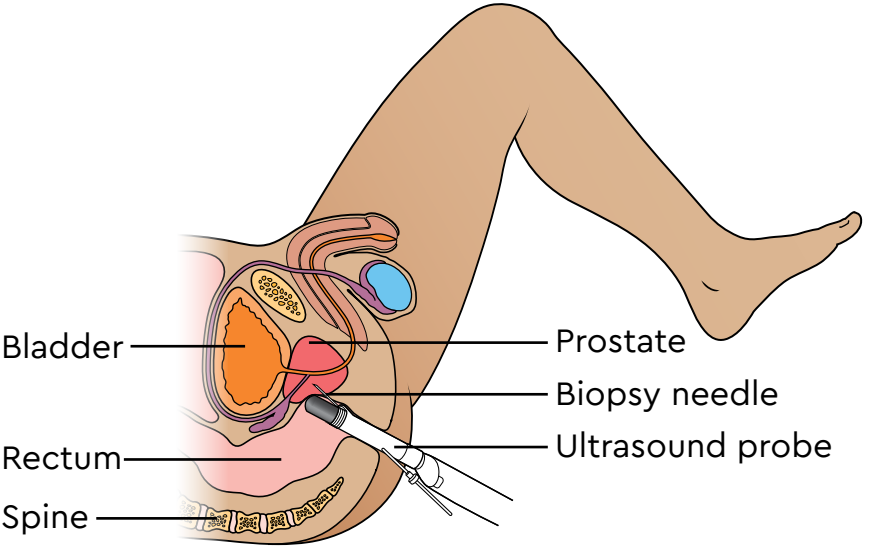
Transrectal ultrasound scan (TRUS) biopsy

Before a TRUS biopsy, you will change into a hospital gown. You will be asked to lie on the couch on your left side, with your knees pulled up to your chest.

The doctor will do a rectal examination before they gently pass a small ultrasound probe into the rectum using lubricating gel. The ultrasound shows an image of the prostate on a screen. The images from your MRI scan may also be used. Then the doctor will inject local anaesthetic around the prostate. This helps reduce any pain or discomfort.
The scan image helps the doctor guide a needle along the probe and into the prostate to take the biopsy. The doctor usually takes 10 to 18 small samples of tissue. You may hear a clicking noise as the samples are taken.

A TRUS biopsy usually takes around 20 to 30 minutes.

Having a TRUS biopsy



What to expect after a prostate biopsy

When you go home, it is important to follow the advice your doctor or nurse gave you. The nurses should tell you what to expect as you recover. They can talk to you about getting back to your usual activities, such as exercise, sex, work or driving.

If you receive anal sex, you should avoid this for a few weeks after a TRUS biopsy until the area has healed. Talk to your doctor or specialist nurse if you need more advice.

If you are unsure about anything, ask questions for more information. Ask who you should call if you have any questions or concerns after you go home.

You will be given a discharge letter. A copy will also be sent to your GP. You may be given some antibiotics to take to help prevent infection.

You may have some pain or discomfort after the procedure. This is bruising from where the samples are taken. Taking painkillers can help – for example, ibuprofen. Check with your doctor which painkillers are suitable for you.

You may have a small amount of blood in your pee for up to 2 weeks. After a TRUS biopsy you may also have blood in your poo. You may also have blood in your semen for a few weeks. Occasionally, having a TRUS biopsy can cause problems with erections while your prostate recovers from any bruising.

Drink plenty of fluids to help reduce the risk of a urine infection. Contact your GP if you have pain passing urine (peeing) or your pee is cloudy or smelly.

Contact a doctor straight away if you:

- have a lot of bleeding
- feel shivery with a temperature over 37.5°C (99.5°F)
- have difficulty passing urine even though you are drinking lots.

Your test results

It can take 2 to 4 weeks to get the results of a biopsy. When your results are ready, you will have an appointment with your urologist. You may also meet a specialist nurse. It may be helpful to take someone with you to this appointment. This can help you to remember what was said. You might also like to write down any questions you have. We have more information on our website at macmillan.org.uk/talk-healthcare-team

The urologist and specialist nurse will talk to you about your test results and what they mean. If you are diagnosed with prostate cancer, the urologist will advise having further tests to help plan treatment. Not everyone will need more tests.

A group of specialists will discuss your results and plan your care and treatment. This is called a multi-disciplinary team (MDT). Your doctor will then explain the different treatment options and their side effects. They may give you a choice of treatments. Sometimes different treatments are thought to work equally well in treating prostate cancer. Your personal preferences are also important. You may decide on a treatment based on what it involves and its side effects.

Staging tests

Whether you have any further tests can depend on the stage and grade of the cancer. Prostate cancer is divided into risk groups. Doctors work out your risk group by looking at different factors:

- the PSA level
- the stage (the size of the cancer and how far it has spread) – this information comes from the scan result
- the grade of the cancer (the Gleason score or Grade group) – this is how quickly it might grow, and the information comes from the biopsy result.

Sometimes the tests are also used to diagnose and stage prostate cancer. You may not need all of them. Knowing the stage and grade of the cancer helps you and the MDT decide on the best treatment options.

Your doctor can explain the benefits and disadvantages of each test before you agree to have any of them. They will also tell you how and when you will get the results.

MRI scan

An MRI can show if the cancer has spread outside the prostate to areas nearby. The procedure is the same as for a multi-parametric MRI scan (mpMRI scan).

CT scan

A CT scan makes a 3D picture of the inside of the body using x-rays taken by the CT scanner. You may have a CT scan if you are unable to have an MRI due to the magnet.

It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 10 to 30 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly backward and forward through the doughnut-shaped scanner.

We have more information about having a CT scan on our website. Visit macmillan.org.uk/ct-scan

Bone scan

The bones are the most common place for prostate cancer to spread to beyond the lymph nodes.

A bone scan uses a low dose of radiation to show abnormal areas of bone. Abnormal bone absorbs more radioactivity than normal bone, so it looks different on the scan pictures.

Abnormal areas of bone seen on the scan are sometimes called hot spots. Hot spots are not always cancer. They may be changes to the bone caused by normal healing or by other health conditions, such as arthritis.

You have the scan in the x-ray department at the hospital.

The person who works the scanner is called a radiographer. About 3 hours before the scan, they inject a radioactive substance into a vein, usually in the arm. This substance is called a tracer. Rarely, some people are allergic to it. Tell the radiographer straight away if you feel breathless, sweaty, weak or unwell.

The scan takes about 30 to 60 minutes. You lie on a narrow bed. The bed moves slowly backward and forward through the scanner. You can usually go home after the scan. The amount of radioactive tracer used is small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

Staging, grading and risk groups for prostate cancer

The stage of a cancer describes its size and how far it has spread. The results of your tests help your doctors determine the stage.

The grade of a cancer is based on what the cancer cells look like under a microscope. Prostate cancer is divided into Grade Groups.

Early and locally advanced prostate cancer are also grouped into risk groups. Doctors use the risk group to help them plan treatment.

Staging, Grade Groups and risk groups can be hard to understand. Always ask a member of your healthcare team to explain your situation to you. They can explain anything that you may not understand.

Staging of prostate cancer

Doctors often use the TNM staging system for prostate cancer.

TNM staging system

T describes the size of the tumour in the prostate.

N describes whether the cancer has spread to any lymph nodes.
N0 means the cancer has not spread to the lymph nodes.
N1 means there is cancer in one or more lymph nodes close by.

M describes whether the cancer has spread to another part of the body. This is called metastatic cancer. M0 means the cancer has not spread to another part of the body. M1 means the cancer has spread to other parts of the body.

Grading of prostate cancer

The grade of a cancer describes:

- how the cancer cells look
- how likely they are to grow and spread outside the prostate.

Doctors will take several samples of the cancer cells during a biopsy. Then they will look at these samples under a microscope.

Grade Groups are a system to describe the grade of a prostate cancer. They are based on the Gleason score.

Gleason score

This looks at the pattern of cancer cells in the prostate tissue, and how different they are to normal prostate cells.

There are 5 different patterns, graded from 1 to 5. Grades 1 and 2 look like normal prostate tissue. Prostate cancer is Gleason grade 3, 4 and 5. Grade 5 is very different to normal tissue.

There may be more than one grade present in the biopsy. The doctor examines all the biopsy samples taken and identifies:

- the most common grade
- the highest grade.

They add these together to give the Gleason score. For example, if the doctor finds the most common grade is 3 but the highest other grade

seen in a sample is grade 4, then the Gleason score is 3 + 4 = 7.

Grade Group

The Grade Group is a number between 1 and 5. The lower the Grade Group, the less likely the cancer is to grow and spread.

Group 1 – Gleason score 6 (3+3)

The cancer cells look very similar to normal cells and are likely to grow very slowly, if at all.

Group 2 – Gleason score 7 (3+4)

Most of the cancer cells look like they will grow very slowly. Some may grow at a moderate rate.

Group 3 – Gleason score 7 (4+3)

Most of the cancer cells look like they will grow at a moderate rate. Some may grow very slowly.

Group 4 – Gleason score 8 (3+5, 4+4, 5+3)

The cancer cells look like they will grow at a moderately fast rate. Some may look like they will grow quickly.

Group 5 – Gleason scores 9 (4+5, 5+4) and 10 (5+5)

The cancer cells look like they will grow at a moderately fast rate or quickly.

Risk groups for prostate cancer

Prostate cancer can be described as low, intermediate or high risk.

Prostate cancer is also divided into 5 risk groups. Your doctor will look at:

- the T stage of the cancer
- your Grade Group
- your PSA level.

They can then identify a risk group. The Cambridge Prognostic Group (CPG) is a system that can help your doctors decide on the best treatment for you based on your risk. There are 5 risk group scores, from CPG1 to CPG5.

We have more information about staging, Grade Groups and risk groups for prostate cancer at macmillan.org.uk/prostate-cancer

Talking to your healthcare team

You probably have lots of questions. Understanding what is happening and why can make you feel more involved in your care. It can also make it easier to make decisions.

Your main point of contact at the hospital is your key worker. This is usually your specialist nurse. A team of healthcare professionals is responsible for your treatment and care. This is called a multi-disciplinary team (MDT). We have more information about MDTs on our website.
Visit macmillan.org.uk/MDT

Members of your MDT and your key worker can answer any questions you have. They can also refer you to other people who can help.

Difficult questions

Some questions may be difficult to ask, particularly when they are about very personal issues. For example, you might want to talk about the impact that a cancer diagnosis and treatment might have on your sex life. Or you may want to ask about symptoms you are experiencing that feel embarrassing. We have more information in our booklet Cancer and your sex life.

You may feel embarrassed or afraid to ask these questions. But healthcare professionals are used to all kinds of questions and are happy to help. They will have helped many other people in similar situations.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.

Tips for asking questions

Here are some tips to help you get the answers you need when you have questions for your healthcare team.

Appointments and other chances to speak with your healthcare team can be short. To make the best use of your time, it is good to be prepared. We have information to help you prepare for an appointment. Visit macmillan.org.uk/talk-healthcare-team

It may help to write down your questions before your appointment. Keep a notebook handy and write things as you think of them. There is space to write down questions and notes.

You can make notes during appointments in a notebook. This may help you to remember what is said. You can also get copies of any documents your cancer doctor or healthcare team send to your GP. This might include information about your test results.

Some healthcare professionals may be happy for you to record consultations using a voice recorder or smartphone. You must ask their permission first.

You may find it helpful to bring someone with you to appointments, such as a family member, friend or carer. They may also be able to make notes while you talk to the healthcare professional, and help you remember what is said.

You may prefer to bring someone with you for support who is not a family member or friend. These people are called advocates.

Advocates are independent of social services and the NHS. They can help you understand and remember information, and help you talk about your thoughts and feelings with your healthcare professionals. They can also help you to make decisions about your treatment and care. You can find more information about patient advocate services from the NHS.

You do not have to ask all your questions at once. There will be other chances to speak to your healthcare team. It is fine if you think of new questions or need to ask a question again. You can make another appointment, or speak to your healthcare team on the phone. Some healthcare professionals can also be contacted by email.

Your key worker should give you their contact details so that you can talk over the phone or arrange a face-to-face meeting. You can use this to discuss anything you do not understand or that you need repeating.

Support to understand information

Some people might need support to get the information they need, or to understand it.

For example, you may:

- have difficulty understanding or speaking English
- have a physical disability that affects your hearing, sight or speech
- have a learning disability.

Or you might find that your healthcare team does not understand your culture and how best to communicate with you.

We have more information on getting support to understand information on our website at macmillan.org.uk/support-understand-information

Your feelings

If you are diagnosed with prostate cancer, you may find it hard to accept. It is common to have a range of different emotions.

We have more information about cancer and your feelings in our booklet How are you feeling? The emotional effects of cancer.

You may get support from your healthcare team. You can usually talk to your GP, urologist, cancer doctor or specialist nurse about what is happening and how you feel. They may be able to arrange more support or someone else to talk to. You can also check for cancer information and support in your area.

Talking to family or friends may also help. But sometimes it is hard to start a conversation about cancer. You may find it useful to read our information on talking about your cancer diagnosis.

Macmillan is also here to support you. If you would like to talk, you can:

- call the Macmillan Support Line on 0808 808 00 00
- chat to our specialists online at macmillan.org.uk/livechat
- visit our prostate cancer forum at macmillan.org.uk/community to talk with people affected by prostate cancer, share your experience, and ask an expert your questions.

"I used the Macmillan Support Line and Online Community. It was lovely to have someone who would listen to all the things that sometimes you're afraid to say to the people closest to you. It helped me put things in perspective. "

David, diagnosed with prostate cancer

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at informationproductionteam@macmillan.org.uk or call us on 0808 808 00 00.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on 0808 808 00 00.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide information to help you manage cancer at work. Visit macmillan.org.uk/work

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Prostate cancer support organisations

Prostate Cancer UK

Helpline **0800 074 8383**
www.prostatecanceruk.org
Provides information and support to men with prostate cancer and their families. Has offices in London, the Midlands, Scotland, Wales and Northern Ireland.

Orchid

Helpline **0808 802 0010**
www.orchid-cancer.org.uk
Funds research into men's cancers and their prevention, diagnosis and treatment. Offers free information leaflets and fact sheets. Has an enquiry service supported by Orchid Male Cancer Information Nurses.

Prostate Scotland

Tel **0131 603 8660**
www.prostatescotland.org.uk
A Scottish charity providing information, support and advice on prostate health and diseases of the prostate. You can watch videos online and download free leaflets and booklets.

Tackle Prostate Cancer

www.tackleprostate.org
An organisation of UK patient-led prostate cancer support groups.

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
www.bladderandbowel.org
Provides information and advice on a range of bladder and bowel symptoms and conditions.

Sex and relationship support

Prostate Cancer UK sexual support service

Helpline **0800 074 8383**
www.prostatecanceruk.org/prostate-information-and-support/get-support/sexual-support
A service for you or your partner to talk to a specialist nurse about sexual problems after treatment for prostate cancer.

General cancer support organisations

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-related and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'Therapist directory'.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This leaflet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr John Frew, Consultant Clinical Oncologist and Dr Ursula McGovern, Consultant Medical Oncologist.

With thanks to:

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Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact informationproductionteam@macmillan.org.uk

Sources

Below is a sample of the sources used in our information about having tests for prostate cancer. If you would like more information about the sources we use, please contact us at informationproductionteam@macmillan.org.uk

National Institute for Health and Care Excellence (NICE). Prostate cancer: diagnosis and management. NICE Guideline [NG131]. Published: 9 May 2019. Last updated: 15 December 2021. Available from: www.nice.org.uk/guidance/ng131 [accessed March 2024].

Castro E, Fizazi K, Heidenreich A, Ost P, Parker C, Procopio G, et al. Prostate cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology. 2020; 31(9): 1119–1134. Available from: www.annalsofoncology.org/article/S0923-7534(20)39898-7/fulltext [accessed March 2024].

Can you do something to help?

We hope this leaflet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, money advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to macmillan.org.uk/donate

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN CANCER SUPPORT

This leaflet is for anyone who may be having tests for prostate cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.

The leaflet explains the different tests you might have for prostate cancer. It has information about what prostate cancer is, how it is diagnosed and what test results mean.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.

Trusted Information Creator
Patient Information Forum