



Prostate
Cancer
Research

pccr.org.uk

Transforming research.
Transforming lives.



Treating prostate cancer

Questions & answers

Information medically fact-checked and reviewed by patients

Why we created this booklet

Every year there are around 52,300 men in the UK diagnosed with prostate cancer. One way of dealing with the disease is through gaining knowledge and information. A diagnosis of cancer is life-changing and often bewildering.

As cancer treatments and options change, it is often hard to navigate the huge amount of information that you are given. This booklet aims to give you an insight into the disease and current treatments in an easily digestible question-and-answer format. You can also visit our new, online patient information website called the infopool.



Scan the QR code to visit the infopool



Feedback on this booklet

If you would like to give feedback on this booklet, scan the QR code or visit: <https://bit.ly/3FNROZb>



www.theinfopool.co.uk

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How can I use this booklet?

This booklet is for those who have already been told they have prostate cancer. It aims to:

- Help you become better informed about prostate cancer and how it is treated.
- Guide you in the decisions you will make about your care with your doctor.

This guide can be used together with our new online patient resource called the infopool.

You will see QR codes throughout the booklet linking you to relevant pages on the infopool.

There are several treatments for prostate cancer, which may sometimes be used in combination with each other. Each treatment has its own risks and side effects and individual experiences may vary.

You should aim to talk through your options with different specialists (e.g., a surgeon, radiologist and medical oncologist), and feel comfortable asking more questions or requesting more time to make the right decision for you.

We have included a tear-out page with a list of suggested questions for you to ask your medical team and space for notes.

Relatives and friends may also find this booklet useful.



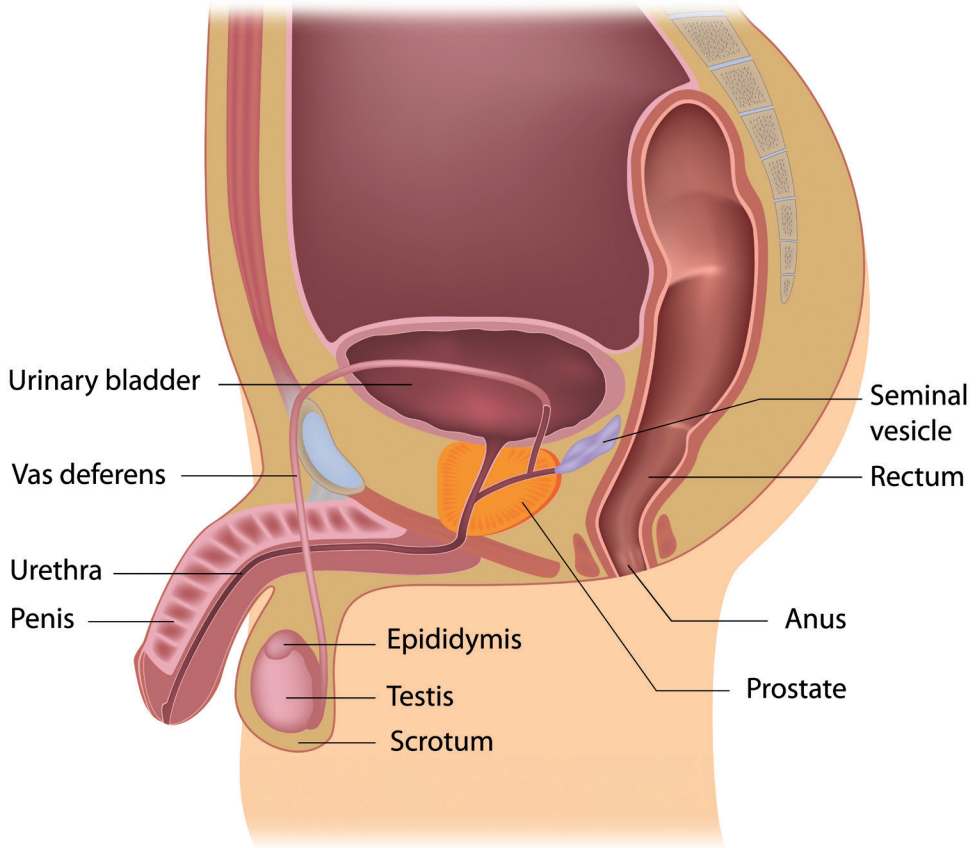
The information in this booklet cannot replace talking to your GP, hospital doctor or nurse.

SECTION ONE

What is prostate cancer and how is it diagnosed?

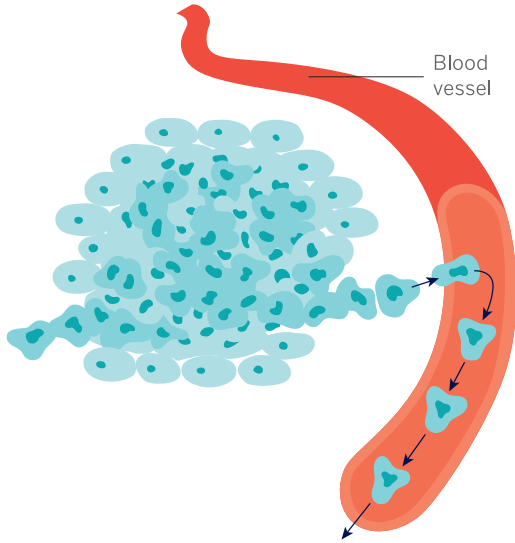


Visit the infopool to learn more about your prostate and what can go wrong



WHAT AND WHERE IS THE PROSTATE?

The prostate is a gland found only in men and is located just below the bladder. When men pass urine, it flows through a tube (urethra) and out through the penis. The urethra has to pass through the prostate before reaching the penis. This is why some men have problems with urinating when they have an enlarged prostate. Fluid produced by the prostate forms part of semen and may help to nourish sperm.



Cancer cells can break away from their original site, travel around the bloodstream and form 'metastases' in other parts of the body.

WHAT IS CANCER?

Your body is made up of trillions of cells that continuously renew themselves to replace old or damaged tissue. When the renewal process gets out of control and begins to invade healthy tissue, it is called cancer. However, cancers are different from benign (non-cancerous) growths, which are more common and do not invade healthy tissue.

All cancers are described as 'malignant'. Other words for describing a cancer are 'tumours' and 'neoplasms'. Sometimes cancer cells break away from the original site and settle in other parts of the body, causing further damage. When this happens the cancers that have spread are called 'metastases' or 'secondaries'.

WHAT GOES WRONG WITH THE PROSTATE?

As men get older, the prostate gland increases in size. Many men will develop a condition called benign prostatic hyperplasia (BPH). BPH is not cancer. Men who have difficulty urinating may have drug therapy or an operation called a TURP (transurethral resection of the prostate) or other surgical and less invasive treatments, to relieve the symptoms of BPH.



Around **1 in 8** men will get prostate cancer at some point in their life.



The risk rises to **1 in 4** for Black men.

Prostate cancer can, in some advanced cases, cause urinary difficulties similar to those for BPH. So, some men with prostate cancer may be offered a TURP. This procedure involves cutting away part of the prostate in order to relieve symptoms associated with an enlarged prostate. It is done under general or spinal anaesthetic so you will not feel any pain, and most patients will need to stay in hospital for around one-to-three nights following the procedure. This operation does not cure prostate cancer.



More than half of men diagnosed with prostate cancer are over 70. Prostate cancer cells usually grow very slowly and many men will live out their whole lives without the cancer being discovered or causing any symptoms.

SYMPTOMS OF PROSTATE PROBLEMS

Listed below are some symptoms that are usually caused by benign disease, not prostate cancer. So do not worry if you have any of these symptoms, but do go to your doctor to have them checked as there are treatments that can help to reduce or eradicate these symptoms.

Difficulty or pain in passing urine

Having to rush to the toilet to pass urine

Frequent visits to the toilet, especially at night

Starting and stopping while urinating

Dribbling urine

A feeling of not having emptied the bladder fully

It is important to note that prostate cancer often has no symptoms.

RISK FACTORS OF PROSTATE CANCER

- **Age** The risk of developing prostate cancer increases as you get older and most cases are diagnosed in men over the age of 50.
- **Race/ethnicity** Black men over 45 have an increased risk of prostate cancer.
- **Family history** You're much more likely to have prostate cancer if your father or brother has had it, especially if they were under 60. Research shows that having a close relative with breast cancer may also increase your risk.
- **Lifestyle** There is some evidence that obesity and diet has an effect.

Learn more about the tests and scans used to diagnose prostate cancer or rule it out using our testing and diagnosis tool



WHAT TESTS ARE THERE FOR PROSTATE CANCER?

Prostate cancer may be suspected following a digital rectal examination or blood test called PSA (Prostate Specific Antigen). However, it can only be confirmed by examining prostate tissue (a biopsy) under a microscope. Sometimes, advanced prostate cancer is diagnosed when men visit the doctor feeling unwell, with tiredness, loss of appetite and perhaps bone pain.



Prostate-specific antigen (PSA) test

PSA is made by the prostate and some of it leaks into the blood. A small sample of blood is taken from a vein in the arm and sent to a laboratory to measure the level of PSA. You may be advised to avoid strenuous exercise and sexual activity for 48 hours before taking a PSA test as they could affect the results. It is also important to tell your doctor about any other medication or procedures you have had as these could also affect your PSA.

Only one in four men with a PSA level between 4 and 10 micrograms per litre has prostate cancer. There are various reasons for a raised PSA level. A high PSA does not

Age	PSA level micrograms/litre
Below 40	Clinical judgement
40–49	More than 2.5
50–59	More than 3.5
60–69	More than 4.5
70–79	More than 6.5
Above 79	Clinical judgement

Age-specific PSA levels for people with possible symptoms of prostate cancer. National Institute for Health and Care Excellence (NICE) 2023.

necessarily mean you have cancer. Similarly, a lower PSA does not necessarily mean you do not have cancer.

As it is generally felt that the PSA test is an insufficiently accurate indicator of prostate cancer, you may find it helpful to undergo regular PSA tests to detect any changes early. Any man over the age of 50 is entitled to a free PSA test under the NHS informed choice programme, called Prostate Cancer Risk Management.



Digital rectal examination (DRE)

You will be asked to lie on a couch on your side with your knees drawn up towards your chin. The doctor or specialist nurse will then put a gloved finger up into your bottom. He or she will be able to feel your prostate through the rectum wall. Possible signs of prostate cancer include a prostate that feels hard or lumpy.

FURTHER TESTS

Your GP will ask you to describe how you feel. Depending on the results of the digital rectal examination, and the urine and blood tests, your GP may refer you to a hospital for further investigation by a surgeon (urologist). We describe these investigations over the next two pages.



MRI (magnetic resonance imaging)

Magnetic resonance imaging scans the prostate to look for abnormal areas. If after a prostate biopsy prostate cancer is diagnosed, the scan will help determine how much cancer is present.

In most centres, a multi-parametric MRI (mpMRI) is carried out prior to prostate biopsies. If no suspicion of prostate cancer is found during the mpMRI, a patient may not need to undergo a biopsy. Other centres may be unable to carry out an mpMRI first, so will schedule MRI scans after prostate biopsies. The MRI machine is a large cylinder surrounded by a magnet.

For the scan, you will lie on a moveable table that will slide into the MRI machine for the picture of your prostate to be taken.



Learn more about MRI scans

LIKERT SCORE AND PI-RAD SCALE

Images from the MRI are used by the radiologist to give you a Likert score. Your Likert score indicates how likely it is that you have prostate cancer and will range from 1 to 5. You could also be given a PI-RADS score, which uses a similar 1-to-5 scoring system.

Likert score	PI-RADS score	What this means
1	1	It is very unlikely that you have prostate cancer that needs treating.
2	2	It is unlikely that you have prostate cancer that needs treating.
3	3	It is difficult to see if cancer is present or not.
4	4	It is likely that you have prostate cancer that needs treating.
5	5	It is very likely that you have prostate cancer that needs treating.

Likert score and PI-RADS scale.



Prostate biopsy

You will usually be asked to lie on your back with your knees bent and thighs apart or your legs in stirrups. An ultrasound probe is put into your back passage.



Learn more about prostate biopsy

A fine needle is inserted either through the area between your testicles and back passage (transperineal biopsy) or through your back passage (transrectal biopsy). The number of samples (biopsies) taken depends on your PSA level and your MRI scan report. Biopsies are usually carried out under a local anaesthetic. This means the doctor will numb the prostate, the area surrounding the prostate and the area between the back passage and the testicles (perineum). Sometimes a general anaesthetic is used. The samples are sent to the laboratory to be viewed under a microscope. You may also have a course of antibiotics in order to prevent infection.



Bone scan

A bone scan shows any spread of cancer into the bones. A tiny amount of radioactive substance is injected into your veins and taken up by abnormal bone. The images will be taken several hours after the injection. Any spread of cancer to the bones shows up as dark areas.



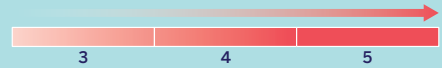
Learn more about bone scans

You may also have a CT scan or MRI scan. These help to tell the difference between early and late prostate cancer.

CANCER AGGRESSIVENESS (GLEASON SCORE)

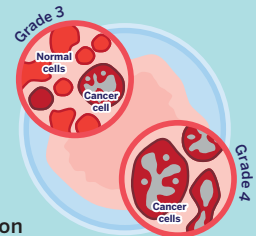
Your biopsy is used to get a Gleason score. Each sample from your biopsy is graded from 3 to 5.

Less aggressive More aggressive



Gleason Score	Risk
6 (3+3)	Low
7 (3+4)	Medium
7 (4+3)	Medium
8 (3+5), 8 (4+4), 8 (5+3)	High
9 (4+5), 9 (5+4), 10 (5+5)	High

Prostate cancer cells can look very different across the whole sample. This means that different areas of your cancer may have different grades. Your Gleason score is made up of two grades. They are added together to give the final Gleason score. It ranges from 6 to 10.

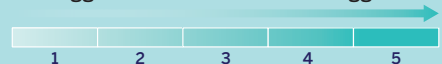


Sometimes the Gleason score is also referred to as the Grade Group. This is how they match up.

Grade Group	Gleason Score	Risk
1	6 (3+3)	Low
2	7 (3+4)	Medium
3	7 (4+3)	Medium
4	8 (3+5), 8 (4+4), 8 (5+3)	High
5	9 (4+5), 9 (5+4), 10 (5+5)	High

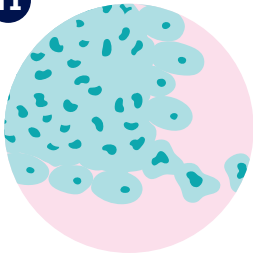
There are five Grade Groups. Grade Group 1 is the least aggressive. Grade Group 5 is the most aggressive.

Less aggressive More aggressive



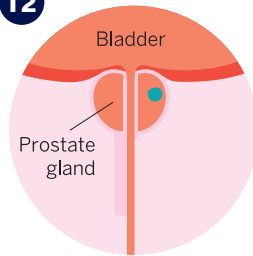
CANCER STAGING: HOW FAR HAS THE CANCER SPREAD?

Prostate cancer is described as 'localised', 'locally advanced' or 'advanced'. It starts with changes in the cells of the prostate. The cells form a lump that may eventually be felt in a physical examination. Cancer spread is described according to 'TNM stages', standing for primary Tumour, Nodes and Metastasis. The T stage tells you the size of the tumour. The N stage tells you whether the cancer has spread to the lymph nodes. Nodes can be N0 (negative) or N1 (positive). N1 indicates that the cancer has spread outside the prostate to one or more local lymph nodes. The M stage tells you whether the cancer has spread to other areas in the body. Metastasis can be M0 (negative) or M1 (positive). M1 indicates that the cancer has spread to other parts of the body.

T1


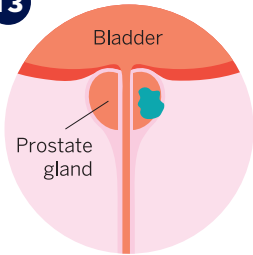
T1 stage

Early prostate cancer that can only be seen under the microscope.

T2


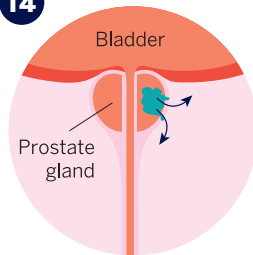
T2 stage

Early prostate cancer that can be felt by rectal examination.

T3


T3 stage

Locally advanced prostate cancer that may cause urinary problems.

T4


T4 stage

Late prostate cancer probably with secondaries or metastases.



What treatment is best for you?

Over the course of the rest of the booklet you will learn about the different treatments available for prostate cancer. If you are not sure of what treatment options are suitable, you can also visit the infopool and look at our treatment tool or treatment comparison table.

Scan the QR code to view the treatment tool



Scan the QR code to view the treatment comparison table



SECTION TWO

How is early prostate cancer treated?

What are the treatments for early prostate cancer, and which is right for me?

Early cancers are usually dealt with in one of three ways:



Monitoring

Through active surveillance or watchful waiting



Radical prostatectomy

Find more information in Section Three



Radical radiotherapy or brachytherapy

Find more information in Section Four

Although any one of them may be most appropriate for you, these treatments can have very different effects on your quality of life. So you have an important part to play in making an informed choice.

WHAT IS MONITORING?

Some prostate cancers grow slowly and may not affect life expectancy. In this case, your doctor may recommend observing your cancer, rather than beginning treatment. This can avoid unnecessary treatment and side effects. The two ways of monitoring prostate cancer are active surveillance and

watchful waiting. There is a small chance the cancer may grow more quickly than expected but this is unlikely. If the cancer starts to grow or you change your mind about your treatment, your doctor will discuss the available options with you.



What is active surveillance?

Active surveillance involves regular check-ups to monitor your prostate cancer. You will have to go to an outpatients' clinic or GP surgery for regular PSA tests and sometimes repeat scans, DRE and biopsies. The doctor will be looking for a rise in your PSA level or any change in your condition. Active surveillance is often the best option for those with low-risk prostate cancer.



Learn more about active surveillance



What is watchful waiting?

Watchful waiting also involves check-ups to monitor the prostate cancer but these do not usually involve DRE and biopsies. It is often the best option for those who won't benefit from treatment or those whose cancer won't cause problems during their lifetime.



Learn more about watchful waiting

Patient voices



'I ended up being on active surveillance for about nine years. Overall, it was a fairly good journey and like anything around prostate cancer with regular tests and things you have times of stress but it was manageable.'

Simon – *active surveillance*

'My health is fine, my fitness levels are fine but every so often you have dark days, but there is always sunshine and every day is a new day.'

Maurice – *watchful waiting*



Overall survival



98 out of **100** people offered active surveillance had **NOT** died of prostate cancer at 10 years

This figure is for those with Cambridge Prognostic Group 1, 2 and 3 localised prostate cancer. Your doctor will use a system called the Cambridge Prognostic Group to calculate your risk. They use this to help them decide what treatment is best for you. Ask your doctor or nurse specialist for your grading. Also take a look at the grading and staging of prostate cancer page on the infopool.



SECTION THREE

Radical prostatectomy

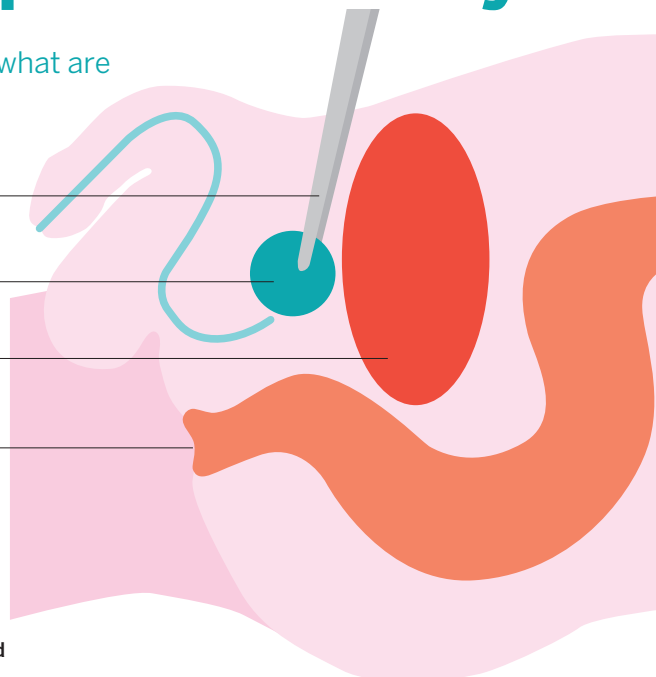
What is involved and what are the risks?

Forceps

Prostate

Bladder

Rectum



The whole prostate is removed in a radical prostatectomy.

A radical prostatectomy is a major operation in which the whole prostate is surgically removed. The aim is to remove all of the cancerous cells. This is different to a TURP (see page 3), which only removes some of the prostate. Visit the infopool for more information and to watch an animation about radical prostatectomy.

WHO SHOULD CHOOSE TO HAVE A RADICAL PROSTATECTOMY?

The surgeon (who can carry out a radical prostatectomy) and the clinical oncologist (who can offer you radical radiotherapy) will help you decide between active surveillance and radical prostatectomy and radical radiotherapy.

Radical prostatectomy is generally only recommended for men with a life expectancy of at least 10 years. Your decision may be influenced by the side effects of each option and how they might affect your quality of life.



If you think your life expectancy is limited, you may feel the side effects of surgery on your quality of life may not be worth any possible gain. Even if your life expectancy is not limited, you may be more concerned about your quality of life. This is a decision only you can make.

HOW IS A RADICAL PROSTATECTOMY CONDUCTED?

Radical prostatectomy can be done by a variety of routes. Depending on where the tumour is, the surgeon may be able to save some of the nerves on either side of the prostate, which will affect the side effects. Your consultant should be able to discuss this with you. Surgery can be open, in which case a surgeon will make either an abdominal (retropubic) cut or cut between the testicles and the back passage (perineal), or keyhole surgery (laparoscopic or robot-assisted surgery). Keyhole surgery involves a number of smaller incisions. The availability of robot-assisted prostatectomy is increasing across the UK, and is now available in centres in England, Wales, Scotland and Northern Ireland, but may not be available in all hospitals.



Our local services search tool will allow you to search for hospitals near you that offer robot-assisted prostatectomy. Just scan the QR code.

Your PSA should fall to a very low level after the operation. As long as it does not rise, it is generally considered that you are free of the cancer. Further treatment with hormones, radiotherapy or chemotherapy may be needed if the PSA blood test still shows that cancer is present after surgery. The timing of any further treatment will depend on the rate of rise of your PSA level.

WHAT ARE THE SIDE EFFECTS OF A RADICAL PROSTATECTOMY?



Up to around one in five men

suffer mild urinary incontinence. This means you may leak urine when you cough. Incontinence is often temporary. You will be shown how to do pelvic floor exercises to improve continence.



Up to seven in every 100 men

suffer major problems with urinary incontinence. This causes continuous leakage of urine. Incontinence is often temporary.



Almost all – but not all – men

will have some difficulty getting erections (impotence), although many will recover to some extent.



All men will be infertile and have a dry orgasm.



Some men have problems passing urine owing to scarring at the new join between the urethra and the bladder.

Treatments are available for impotence and incontinence that your doctor can discuss with you. It is possible to store sperm before treatment for later use in IVF, if you think you may want to have children later. Incontinence is usually temporary, and you may find pelvic floor exercises reduce your risk and help you to recover.

Scan the QR code for more information and to watch an animation about radical prostatectomy



WHAT DOES THE OPERATION INVOLVE?

Radical prostatectomy is a major operation with risks and complications. The time you will have to wait for your operation will vary depending on where you are, but current targets are within 62 days of the hospital receiving your referral. Bring any medication you are taking with you and show this to the nursing staff or doctor.

At the hospital

You will be asked to go to the hospital before the operation for routine checks, including:

- **Your blood pressure, pulse and temperature**
- **A urine test**
- **An ECG (tracing your heartbeats electrically)**
- **Blood tests**
- **A chest X-ray.**

Usually, you will be admitted either the day before or early on the day of your operation. Make sure that you do not eat or drink anything in the six hours before surgery, though you may be able to drink water until a few hours before your operation. Your medical team will explain this to you. On the day you go to hospital, you may have your blood pressure, pulse and temperature checked again. Most men are in hospital two-to-four days for laparoscopic and open surgery, or one-to-two days for robotic surgery, but this can vary.

What happens before the operation?

The anaesthetist who will be looking after you during the operation will visit you and ask you questions about:

- **Previous operations and anaesthetics** This is to make sure you have had no problems with anaesthetics in the past.
- **Medicines** It is important that the anaesthetist knows about the medication you are taking.
- **Dental problems** The anaesthetist will have to put a tube in your mouth to help you breathe during the operation. It is important for them to know about your caps and crowns. False teeth will need to be removed before undergoing a general anaesthetic.
- **Chest problems and smoking** If you smoke, you are more likely to suffer complications from surgery. You should give up smoking at least a week before you go into hospital. Smoking is forbidden in hospital.
- **Allergies** You must tell the anaesthetist about any allergies you have.
- **Being overweight** You may be asked to lose weight before the operation.



The surgeon will also take precautions to prevent you developing a blood clot. You may be asked to wear elastic stockings and be given injections of blood-thinning drugs.

A patient's voice



'I would have the same treatment again, because if I can go back in time, I know how it happens and it worked well for me and has been successful.'

Ian – *radical prostatectomy*



Overall survival



99 out of **100** people offered radical prostatectomy had **NOT** died of prostate cancer at 10 years



Learn more about grading and staging

This figure is for those with Cambridge Prognostic Group 1, 2 and 3 localised prostate cancer. Ask your doctor or nurse specialist for your grading.

What do I need to know about 'consenting to treatment'?

The consent form is a formal agreement between you, the surgeon and the hospital. It says that you are willing to have the treatment shown on the form. It is important that you read the consent form carefully and ask hospital staff any questions you have about it before signing. The surgeon operating on you, or one of their doctors, should bring the consent form to you to sign. You might also be asked to agree to provide spare prostate tissue for research or take part in a clinical trial (see page 33). **This will be your decision. It is important you are aware of the side effects of treatment before you sign a consent form.**



A patient's voice

'Pelvic floor exercises are a must to prevent leakage...make sure you start them before you have your treatment for a better outcome. With regards to erectile dysfunction, there are a number of treatments available, if one doesn't work, don't give up, try another.'

Gary – *radical prostatectomy*

What happens just after the operation?

After the operation you will be taken to the recovery ward. Here, a nurse will check your pulse and blood pressure regularly.

You will have to wait before you have a drink because the anaesthetic may make you feel sick. You will receive food and drink gradually. However, within 24 hours you should be able to eat and drink normally. If you feel sick or have some pain, tell the nurse, who can give you something to help. It will help you recover quicker if you are free of pain, so it is important to tell the nurse if you need painkillers.

Your catheter will stay in for about one-to-three weeks, so you will take it home attached to your leg. (Do not worry, though: it is easy to hide this.) It is important to keep the catheter clean to help prevent infection. A daily bath or shower will help, but if you notice any discharge or pain around the tip of your penis, tell your nurse or doctor. You should try to drink two litres of fluid each day. After the operation, there may be blood in your urine. This is fairly normal.

Occasionally a blood clot forms and blocks the catheter, preventing the urine from coming out. This can be painful and you should tell a nurse or doctor so they can remove it for you.

What happens in the days after the operation?

You will have a bag of fluid above your bed called a drip (intravenous fluids), which runs through a needle into your arm. This will probably be removed

within a few hours. You will have a catheter (plastic tube) passing through your penis into your bladder to drain urine. You may also have one or more plastic tubes in your belly that are attached to drainage bags by your bed – these either drain urine from your bladder or any fluid from the site of the operation. The drain tube is usually removed a day or two after surgery.

You may experience some pain in the first few days. But it is important to walk around after the operation to help prevent clots forming in your legs. If you need painkillers, ask for them.

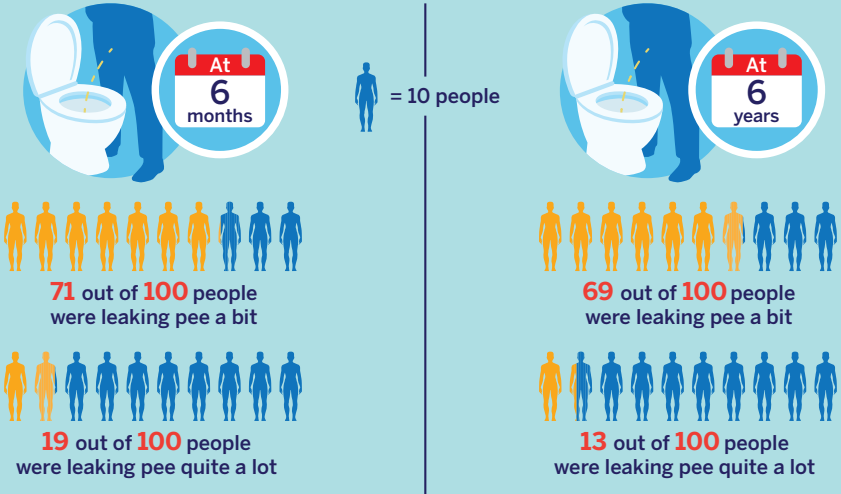
What happens when I go home?

Although you should take it easy for a month, it is important to take some gentle exercise such as walking, as you will still be at risk of developing clots in your legs. Standard over-the-counter painkillers should be enough to deal with any pain but you should seek advice from your doctor/pharmacist.


You will be given a drainage bag for your catheter that you can strap to your leg. One-to-three weeks after you go home, you will have to return to the hospital to have the catheter removed. This is not usually painful although it can be a bit uncomfortable.

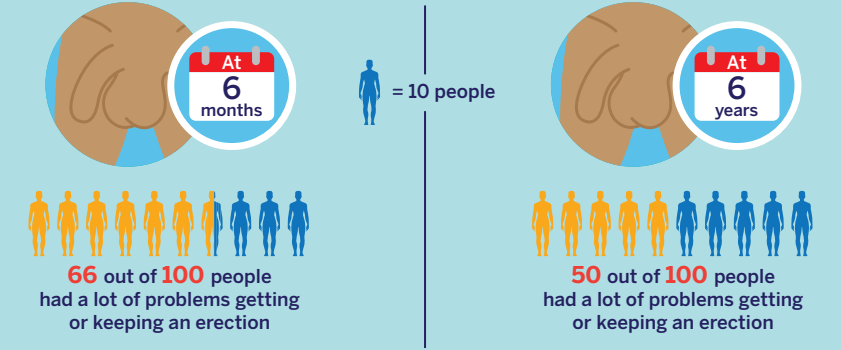
If you had clips rather than dissolvable stitches, you will have these removed by the nurse at your GP's surgery. This is not usually painful. You can return to work when you can comfortably and safely do your job. You will probably still feel more tired than usual for the first month following surgery.

 **Problems peeing (urinary incontinence)**



You may need to use pads if you have problems leaking pee and poo. Your healthcare team will be able to help you manage these problems.

 **Problems getting or keeping an erection (erectile dysfunction)**



These figures are for those with Cambridge Prognostic Group 1, 2 and 3 localised prostate cancer. Ask your doctor or nurse specialist for your grading.



Learn more about grading and staging

SECTION FOUR

Radical radiotherapy

What is involved and what are the risks?

Radical radiotherapy is suitable for men of any age and is an effective alternative to surgery. The aims of radiotherapy are to destroy prostate cancer cells and to stop them from growing.

You can receive radiotherapy in one of two ways:

- **External beam radiotherapy**
High-energy X-ray beams aimed at the prostate from outside the body.
- **Brachytherapy** Small radioactive sources positioned inside the prostate. There are two types of brachytherapy that can be used for different stages of prostate cancer and these are described on page 19.

WHO ARE THESE TREATMENTS MOST SUITABLE FOR?

As with surgery, radical radiotherapy is recommended for men with a good life expectancy. It is an alternative for men whose cancer can be treated radically, but who are not fit enough or choose not to have an operation.

Radiotherapy does not have the same risks that are associated with surgery, such as blood clots or blood loss. You will not have to stay in hospital during the therapy and many men are able to continue with their normal daily activities. However, it is not a 'softer option' – it carries its own risks and side effects, which you must consider before making this choice.



External beam radiotherapy

External beam radiotherapy is used to treat prostate cancer by aiming beams of high-energy X-rays at the prostate gland and the tissues immediately around it. The X-rays damage cells and stop them from growing. Cancer cells are not able to recover from this damage, but the cells in the normal tissues surrounding the prostate (bladder and bowel) can repair themselves more easily. It can be used in conjunction with chemotherapy or used after surgery (adjuvant radiotherapy), in order to make those treatments more effective.

The first step in external beam radiotherapy is to have a special planning scan (CT scan) of your pelvis. This is done to see exactly where in the prostate the cancer is and whether it has spread to areas around the prostate gland or other parts of your body. The information on this scan will allow your doctor (oncologist) to see exactly where your prostate cancer is





Learn more about
grading and staging



Overall survival



99 out of **100** people
offered radical radiotherapy had **NOT**
died of prostate cancer at 10 years

This figure is for those with Cambridge Prognostic Group 1, 2 and 3 localised prostate cancer. Ask your doctor or nurse specialist for your grading.

and map the areas that need treatment.

During the scan the doctor will place small, permanent marks (dots the size of a freckle) of ink onto your skin. These permanent 'dots' will be used to ensure that the exact same area is treated for each of your treatment sessions.

The doctor may ask a radiotherapy physicist to make an individual plan for your treatment. They will use a computer program to decide exactly where the X-rays need to be aimed to treat your prostate gland while trying to avoid as much of the normal tissue in the surrounding areas (bowel, bladder) as possible. This process is very complicated and can take up to a few weeks to be completed.

When the doctor is satisfied with your plan, you may need to go back to the radiotherapy department for a final check to position the X-ray beams before the actual treatment starts. (This is known as a verification visit.)

The X-rays are made in a special machine

called a 'linear accelerator'. When you go for treatment, the radiographer will ask you to lie on your back on a firm bed attached to the machine. Part of the machine will move around you and direct X-rays at your prostate from different directions.

The treatment will only take a few minutes and is completely painless. It is important that you lie very still while the treatment is being given. Before each treatment you will need to have a small enema to empty your bowel and to have a full bladder. This moves your small bowel, rectum and bladder away from your prostate and helps to reduce any side effects. Sometimes a 'spacer' is used to protect your rectum. This helps to move your rectum away from the treatment area. The most common type of spacer is a gel. Currently, these are only used in certain hospitals but will soon be more widely used. Ask your doctor about rectal spacers.

You can expect to have between 20 and 40 treatment sessions over four-to-eight weeks as an outpatient from Monday to Friday (not weekends).

There are two main types of external beam radiotherapy that are available and these use different methods to reduce the amount of radiation given to the normal tissues surrounding the prostate gland. This can reduce side effects and also allow higher doses of radiation to be concentrated on the prostate gland itself.

3D conformal radiotherapy (3D-CRT)

3D-CRT uses special 'blocks' within the linear accelerator to shape the beams to fit the exact shape and size of your prostate.

Intensity-modulated radiotherapy (IMRT)

IMRT uses a computer-driven machine that moves around you as it delivers the radiation. It can be used to adjust the dose of radiotherapy given to different parts of the treatment area, which can then limit doses of radiation reaching nearby normal tissues.

Your doctor may recommend that you take a course of hormone therapy (see page 25) before radiotherapy to shrink the prostate, and maybe afterwards for some months.

OTHER TYPES OF EXTERNAL BEAM RADIO THERAPY

Image-guided radiotherapy (IGRT)

IGRT is usually done alongside IMRT. With IGRT, images are taken before or during radiotherapy that show the size, shape and location of the tumour to allow the doctor to make minor adjustments in aiming. This helps to deliver the radiation even more precisely and results in fewer side effects.



A patient's voice

'The side effects are bad but you must compare them to not being alive. "You are stronger than you think" is something I was always told, and you will get through this.'

Steve – *external beam radiotherapy*

Stereotactic body radiation therapy (SBRT)

SBRT uses advanced image-guided techniques to provide large doses of radiation to a precise area. Since there are large doses of radiation in each dose, the entire course of treatment is given over a few days. SBRT is often known by the trade names of the machines that deliver the radiation, such as Gamma Knife and CyberKnife.

Visit the infopool for more information on external radiation and to read stories from others who have had external radiotherapy.

Scan the QR code to learn more about radical radiotherapy



BRACHYTHERAPY

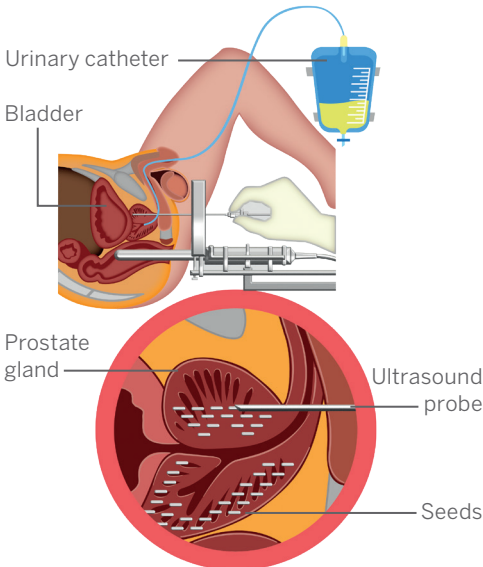
This form of radiotherapy can be given in two ways:

- **Low-dose-rate (LDR) permanent seed brachytherapy**
- **High-dose-rate (HDR) temporary brachytherapy.**

You will be carefully assessed before treatment to make sure that your prostate is not too big, as this treatment can cause difficulties with passing urine if the prostate is very enlarged.

The seeds are placed in the prostate in a similar way to that described for HDR brachytherapy (see page 20). However, the needles are withdrawn and the seeds are left permanently inside the prostate, where they slowly lose their radioactivity with time and treat the prostate cancer.

What happens on the day of surgery?



Although the seeds are radioactive, you are not. As there are low levels of radiation in the seeds, as a precaution you may be asked to avoid close contact with pregnant women and young children for at least two months after the treatment. This treatment can be a quicker alternative for some of the men who cannot visit a radiotherapy centre each day.

This treatment has similar side effects to external beam radiotherapy but the risk of urinary problems is slightly higher and the risk of bowel problems is slightly lower in brachytherapy.



Low-dose-rate (LDR) permanent seed brachytherapy

This is an effective treatment for some men with early prostate cancer and uses radioactive seeds (see diagram left). It can also be effective for some immediate or high-risk patients.

Scan the QR code to learn more about low-dose-rate (LDR) permanent seed brachytherapy



A patient's voice

'The first three months had the highest incidence of side effects, and gradually diminished over the second three months...Talking to your partner, close relatives, or close friends is important, and the follow-up calls from the oncology team can be helpful and supportive.'

Chris – low-dose-rate brachytherapy



High-dose-rate (HDR) temporary brachytherapy

This treatment can be used as well as external beam treatment to allow a higher dose of radiation to be given to the prostate and surrounding tissues for men with locally advanced (see page 25) or high-risk prostate cancer.

Hollow rods or needles are placed in the prostate through the skin of the perineum (the area between the anus and scrotum). You will need an anaesthetic for this procedure. After the needles have been placed, you will have a scan (CT or ultrasound) to check their exact position and your doctor and a physicist will use this information to plan your treatment.

The needles will stay in your prostate until the treatment has finished, during which time you will need to lie on your back and a catheter will be placed in the bladder to help you pass urine. A small radioactive pellet is put in each rod for a few minutes. You will be given the precise dose of radiotherapy that you need based on your treatment plan. The radioactive pellets are then removed after each treatment. Once the radioactive pellets are removed, you will not give off radiation or be radioactive.

You will stay in hospital for a few days until you can pass urine normally after the catheter has been removed. You may have a shorter course of external beam radiotherapy (four-to-five weeks) two weeks after the brachytherapy treatment. The side effects are similar to those from external beam radiotherapy apart from a small extra risk of developing a narrowing of the urethra (stricture) – likely for about one in every 20 men.

WHAT HAPPENS AFTER RADIOTHERAPY?

You will be seen in the outpatient clinic a few weeks after the radiotherapy finishes and regularly for many years afterwards for follow-up appointments. Your follow-up appointments will usually start two or three months after treatment. Your PSA will be checked and you will be asked about any side effects from the radiotherapy treatment. You will be given the chance to ask questions or discuss any concerns.

If your treatment has been successful, your PSA level should fall, which can take many months. If you are also being treated with hormone therapy, the hormone therapy will also reduce the PSA level. You will still have a measurable PSA level because you still have a prostate gland and the normal prostate cells will produce a small amount of PSA.

After radiotherapy, some men experience what is known as a PSA bounce, in which the PSA rises for a short time within the first couple of years after treatment, but then goes back down. Doctors aren't sure why this happens, but it doesn't seem to affect your prognosis.

If your first treatment option was radiation therapy, and the cancer comes back, your other treatment options may include radical prostatectomy. This option will only be available to certain people.

You may be offered a course of hormone therapy injections with your radiotherapy. This can help to shrink your prostate and the cancer inside. Go to pages 25–27 to learn more about hormone therapy and its effects.

WHAT ARE THE SIDE EFFECTS OF RADIOTHERAPY?

Most men experience side effects, but the severity varies from person to person. Acute side effects can happen during treatment and are usually temporary. Late side effects happen after the treatment has finished and these can be permanent. You should be able to continue normal activities during the radiotherapy.

Acute or short-term side effects

These are temporary and usually happen in the last two-to-three weeks of treatment and start to improve a few weeks after the treatment is over. You will be able to get advice about diet and skincare from your radiographer, doctor or nurse. Your doctor will prescribe creams and medicines if you need help with any of these problems.



Sore skin You may experience some darkening, redness and/or soreness of the skin in the area being treated. This is most common in the skin between the legs and around the anus. You should avoid using any creams, lotions or soaps, unless recommended by your doctor, and also avoid hot baths. You may also lose some pubic hair in the area being treated but this will usually grow back.



Bowel changes You may develop some discomfort and pain in the back passage (rectum) and this can be worse when you go to the toilet to open your bowels. This is called proctitis and can be treated with creams and suppositories.

Many men find that their bowel movements become loose and more urgent as the treatment progresses (diarrhoea).

You may also notice a little leakage from the back passage and occasionally some blood or mucus (slime) in the stools. You will be given advice about diet and medication if diarrhoea becomes a problem. The diarrhoea should gradually get better a few weeks after your treatment. However, let your doctor know if it continues.


Some men experience radiation enteropathy, which is inflammation of the intestines after radiation therapy. It can take place early on (acute) when it occurs within three months of radiation therapy, or it can be delayed (chronic) when it occurs between 18 months and six years after radiation therapy. You may experience symptoms such as diarrhoea, nausea, vomiting and stomach cramps. Talk to your doctor if you are experiencing any of these symptoms, as they may recommend changes to your diet and medication.




Bladder changes You may have to pass urine more frequently both during the day and at night. Your urine stream may slow down and you may feel a burning sensation (radiation cystitis) when you pass urine. Owing to the weakening of the blood vessels in your bladder and bowels, you may also notice blood in your urine. If you notice any bleeding in your urine and stools, always tell your doctor so that they can check it out.

Scan the QR code to learn more about high-dose-rate (HDR) temporary brachytherapy





 **Feeling tired** Towards the end of treatment and for a few weeks after, you may feel more tired than usual.


 **Being sick or feeling sick** There may be times that you feel sick. You can take anti-sickness medicines. If you still feel sick after that, let your treatment team know.

Permanent or long-term side effects


Most side effects go away after treatment. However, some continue for many months, come back, or develop years later (these are called late effects). The following side effects can happen after the radiotherapy has finished:


 **Bowel changes** Between one and five men in every 100 will have some long-term bowel changes. These can include diarrhoea or urgency to open your bowels (radiation proctitis), minor bleeding or some mucous from the rectum when passing a motion.

 **Bladder changes** A small number of men may find it more difficult to pass urine. This difficulty will be a gradual process that occurs over a few weeks or months, and is due to the narrowing of the tube from the bladder to the penis (the urethra). Tell your doctor if you have trouble passing urine. About 5% of men have moderate-to-severe problems with leaking urine six years after their treatment ends. If this happens, speak to your doctor as they may be able to refer you to a specialist incontinence clinic.

 **Sexual changes** About 50% of men will have problems getting an erection after radiotherapy. The risk may

increase if you have also been treated with hormone therapy. Treatments may be available to help. Radiotherapy may also cause you to produce less semen and reduce your sperm count, which may lead to infertility. Some men may find this difficult to cope with. If you are worried, talk to your doctor, as you may be able to store sperm before treatment starts.

 **Dry orgasm** This is when you feel the sensation of orgasm but you do not ejaculate. You could also experience retrograde ejaculation, which is when the semen falls into the bladder and is passed out in the urine.

 **Swollen legs or scrotum** Some men experience swelling (known as lymphoedema) in their legs or the sack of skin around the testicles (the scrotum), which can be uncomfortable. This happens because the lymph channels that drain fluid from the legs are damaged by the radiotherapy.



A patient's voice

'The side effects I had with brachytherapy were frequent bowel movements and some soreness for a few days after, but that is all I can really remember.'

Jack – high-dose-rate brachytherapy

SECTION FIVE

Focal therapy

What is involved and what are the risks?

Focal therapies only target areas of the prostate that contain the most significant cancer. There are different types of focal therapy:

- **High-intensity focused ultrasound (HIFU)** uses high-intensity ultrasound waves to kill prostate cancer cells
- **Cryotherapy** (sometimes called cryoablation or cryosurgery) kills cancer cells by freezing them
- **Irreversible electroporation (IRE)**, sometimes called nanoknife) uses electrical pulses to destroy cancer cells.

WHO CAN HAVE FOCAL THERAPY?

You may be able to have focal therapy if your prostate cancer is contained within your prostate and your:

- PSA is less than 20 and
- Gleason grade is 7 (4+3) on your biopsy, affecting just one side of the prostate and the tumour can be seen on an MRI in the same area
- Gleason grade is 6 (3+3), but your tumour size is bigger than 6mm and your MRI (PI-RADS or Likert) score is 3, 4 or 5. This type of tumour could also undergo monitoring instead of using active surveillance. You will need to discuss this with your doctor.

Sometimes a small amount of low-grade cancer, Gleason 6 (3+3), less than 6mm, can be left untreated in other parts of the prostate. These areas are then monitored with active surveillance.



Learn more about focal therapy

ARE FOCAL THERAPIES AVAILABLE VIA THE NHS?

HIFU, cryotherapy and IRE are available from the NHS in England in a few centres under 'special arrangements'. Although these centres are mostly in the south of England, numbers are increasing across the country.

They may be available as part of a clinical trial. Note that if you agree to take part in a trial, there is no guarantee that you will get the treatment you want. They may also be available privately.

WHAT ARE SPECIAL ARRANGEMENTS?

Special arrangements are put in place by the National Institute for Health and Care Excellence (NICE) if there is a lack of long-term data on the effectiveness of a treatment. Before deciding on focal therapy, your healthcare team need to talk to you about:

- What is currently known about focal therapies – the pros and cons
- The uncertainty that surrounds focal therapies.

NICE provides guidance on:

- How different conditions should be treated
- What treatments should be made available.

WHAT ARE THE POSSIBLE BENEFITS OF FOCAL THERAPY?

You are likely to have fewer side effects than you would have with other treatments such as radiotherapy and surgery.

If your cancer comes back and is contained within your prostate, you can still be offered other treatments. This may include radical prostatectomy, radical radiotherapy or even focal therapy again. These will aim to cure your cancer. You may hear them being called salvage treatments.

WHAT ARE THE POSSIBLE DISADVANTAGES OF FOCAL THERAPY?

There is still a risk of side effects as no treatment is side effect-free. This may include problems passing urine, issues with your bowel or erectile dysfunction.

There is more chance of your cancer coming back than with treatments such as radiotherapy and surgery. You may need more surveillance after treatment in case your cancer returns. You can have regular tests that will help to pick up any changes quickly.

It is not yet clear which patients will benefit from focal therapies. Research is ongoing. NICE will update their guidance when more information is known. You may have to travel a distance to get focal therapy.



A patient's voice

'I was lucky that high-intensity focused ultrasound was a possible choice for me because my cancer was discovered at an early stage. It seems to have caused very few side effects and my life was basically back to normal after just a few months.'

David – HIFU



A patient's voice

'I was told that men, in time, can recover from erectile dysfunction. I am now a year and a half on from the therapy and I'm pleased to say that it is getting better with every week.'

Bob – cryotherapy



Survival up to 10 years



Between **99** and **100** in every **100** men were alive 5–10 years after focal therapy

Please note: data relates to cryotherapy and HIFU only.

SECTION SIX

Locally advanced prostate cancer

What is it and how is it treated?

The spread of cancer was described on page 7 in terms of T or tumour stages. When cancer has spread through the capsule of the prostate or the seminal vesicles (T3) or into the surrounding structures (T4), it is called locally advanced prostate cancer. Men with locally advanced prostate cancer have a higher risk that cancer cells may have already spread. You may be offered other treatment to kill any cells that could have spread beyond the prostate.

You may be offered radiotherapy treatment to include the surrounding structures (as well as the prostate), usually in combination with two-to-three years of hormone therapy. Hormone treatment can delay or prevent the cancer coming back in other places and is given by tablets or injections.

Some men with locally advanced prostate cancer are treated with hormone therapy alone. The choice depends on factors that you will discuss with your doctor.



There are two types of hormone treatments that can be used to treat locally advanced prostate cancer:

- **Luteinising hormone-releasing hormone (LHRH) agonists** given by injection (see page 26)

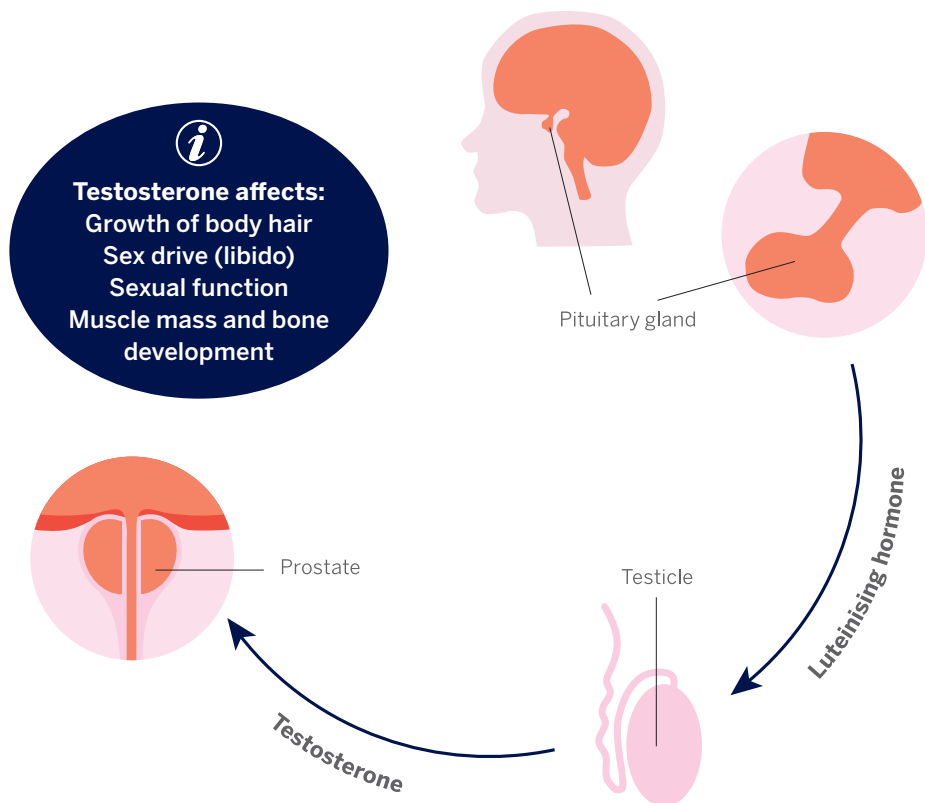
Scan the QR code to learn more about luteinising hormone-releasing hormone (LHRH) agonists



- **Anti-androgens** given by tablet (see page 26).

Scan the QR code to learn more about anti-androgens given by tablet





HOW DOES HORMONE THERAPY WORK?

To grow, the prostate cancer cells need the male hormone testosterone. Hormone treatments work in different ways to prevent testosterone stimulating the prostate cancer cells. The LHRH agonists will prevent testosterone from being produced by the testicles and are given as an injection. The anti-androgens block the action of testosterone on the prostate cancer cells and are given as tablets. **They are both effective in treating this stage of prostate cancer but have different side effects.**

It is important to know that many people will experience emotional as well as physical side effects while on hormone

therapy. Many men on hormone therapy have less energy and feel less motivated, and you may also experience changes in your mood, such as feeling more sentimental, more irritable or more tearful than usual. This is completely normal.

TREATMENT TIMING

We are not yet sure at which stage of prostate cancer introducing hormone therapy is most effective. All those suffering from symptoms should start immediately. However, some doctors like to prescribe hormone therapy for patients with no symptoms. So, you may be asked to decide whether to begin hormone drug therapy immediately or wait until symptoms appear.

WHAT ARE THE RISKS AND SIDE EFFECTS OF ANTI-ANDROGEN DRUG THERAPY?

These drugs allow some men to maintain their sex drive and sexual activity and do not cause any reduction in bone strength, which can be a side effect of LHRH agonists and GnRH antagonists. In some men, the drugs cause loss of body hair, the breasts to grow and sore nipples.

LHRH AGONIST INJECTIONS

These drugs stop the release of a hormone that sends signals to the testicles to produce testosterone. It is a roundabout way of switching off testosterone and so helps to stop prostate cancer from growing.

You may have your first injection at the hospital, but often it is done at your GP surgery. The injections are repeated monthly, every three months or every six months, according to the recommendations of your doctor.



A patient's voice

'After a couple of weeks or so I felt I was getting tired. Try and keep active as much as you can. It's not easy because you feel tired but you need to do it as it has an effect of saving your life.'

Clement – *hormone injections*

What are the risks and side effects of hormone-manipulation drug therapy?

- The majority of men will be unable to have an erection, will lose their sex drive and will be infertile.
- The testes shrink and many men develop hot flushes, grow breasts (gynaecomastia), put on weight around the middle and have mild discomfort in their breasts. Some men lose some strength from the bones and muscles, and this may need to be checked with special bone scans. Some doctors use intermittent hormone therapy to give a rest from the treatment. During the time you are off treatment you may regain your sex drive and have erections.
- As everyone responds differently, it cannot be predicted how long the treatment will be effective. There are other treatments available if you stop responding to the initial hormone therapy. These include adding another type of hormone to your LHRH agonist treatment, such as an anti-androgen (complete androgen blockade). You may be offered treatment with chemotherapy or your doctor may discuss other new drugs that are part of clinical studies.
- LHRH agonist drugs cause an initial surge in the testosterone level, which is counteracted by a short course of anti-androgen tablets before and after the first injection.

Scan the QR code to get tips on how to manage hot sweats and fatigue



SECTION SEVEN

Making informed decisions about your care and treatment

Making good decisions about your care and treatment can feel overwhelming.

MASTERING HEALTHCARE CONVERSATIONS

Attending a healthcare appointment can make some people feel anxious. There are many things you can do to help.



Bring someone else to your appointment

They can take notes, ask questions you may not have thought of and offer moral support.



Prioritise your questions

Focus on questions related to your treatment options, their outcomes and the impact of possible side effects on your everyday life.



Know what to do if you're running out of time

Make sure you get the contact details of your healthcare team before you leave. You can then call or email them any further questions.

It is important that your healthcare team know how you are feeling so that they can help you. Here are five top tips to help you have your say.

Scan the QR code to access our mastering conversations toolkit.



Don't be afraid to share your concerns

Make a list of what has been worrying you the most and share with your team when you arrive.



Always share your symptoms

Tell your team about any new or unusual symptoms. Say whether existing symptoms have improved or worsened. Say how they're affecting your everyday life.



Don't be afraid to talk about sensitive issues

Don't be embarrassed to talk about peeing or sexual problems or your mental health. Your healthcare team have heard it all before.



Don't be afraid to ask questions or say you don't understand

Repeat back what your doctor or nurse says in your own words to make sure you have understood correctly. If you don't understand what they've told you - say so!



Always discuss your treatment options with your healthcare team

Talk to your team about what matters to you most for example, your lifestyle, relationships, sexuality or culture. Don't rush into deciding on a treatment. Take time to talk things over with your family.

WORKING WITH YOUR HEALTHCARE TEAM TO MAKE GOOD DECISIONS ABOUT YOUR CARE

Shared decision making makes sure you are supported to make decisions about your care that are right for you. It involves conversations between you, your healthcare team and your partner or family.

WHY DOES SHARED DECISION MAKING MATTER?

- Improves your knowledge of your condition.
- Helps you feel more confident in your decisions.
- Helps you manage expectations about your treatment.
- Increases satisfaction with your care.
- Minimises treatment regret.
- Increases feelings of control over your situation.
- Ensures you receive more tailored care.

Find out more about shared decision making on the infopool.



10 TIPS ON HOW TO ENGAGE IN SHARED DECISION MAKING

- 1 Decide how much you want to be involved in decisions about your care and treatment and discuss with your healthcare team.
- 2 Involve those around you in the decision making process. You don't have to do this alone.
- 3 Understand your condition. Read trusted sources of information like the infopool.
- 4 Explore all treatment options. Ask your healthcare team to talk to you about all possible options. You can ask to see a surgical and non-surgical doctor.
- 5 Weigh up the pros and cons of each treatment choice. Discuss the benefits and possible side effects with your healthcare team.
- 6 Share your concerns. Discuss with your healthcare team any concerns you have.
- 7 Understand your treatment. Make sure you understand what each treatment involves.
- 8 Consider what matters most. Think about your values, lifestyle and culture.
- 9 Gather all your information together. Share you thoughts with your healthcare team.
- 10 Explore clinical trials. These can be a valuable treatment option for some.

Late or advanced prostate cancer

What is it and how is it treated?

When cancer spreads to other parts of the body (metastasises), it is called late or advanced prostate cancer.

CHEMOTHERAPY

Chemotherapy involves using drugs that can kill or slow the growth of cancer cells by poisoning them. There are many different chemotherapy drugs and some of these have been found to be effective in treating prostate cancer. The most common chemotherapy drug used in the treatment of prostate cancer is docetaxel (Taxotere). Chemotherapy is usually given as injections into a vein. More than one drug may be given. You usually receive these drugs as an outpatient and you may need to go for treatment every few weeks for several months. The exact timing and length of treatment will depend on the drugs that your doctor feels will be most effective. Chemotherapy slows down the growth of both cancer cells and normal cells and can cause side effects.

There are new types of chemotherapy, hormone therapy and other drugs that are being investigated for advanced prostate cancer that are likely to be available in the future. There are also many trials of new drugs and you should speak to your oncologist to see if you would be suitable for one of these trials (see page 33).



What are the risks and side effects of chemotherapy?

The side effects will depend on the drugs that you receive and will usually stop a few weeks after the course of treatment is completed.

Side effects can include feeling sick, but you will be given drugs that are very effective at dealing with this problem. Chemotherapy can sometimes cause damage to the cells in the bone marrow and this can temporarily cause fatigue



A patient's voice

'Chemotherapy stopped my daily life in its tracks, but only for the duration of the treatment. Tiredness, fatigue, weakness, breathlessness, rapid body changes, chemo brain (yes, it's a real thing) and being immunocompromised impacted every part of my normal routine.'

Joe – chemotherapy



and make you more prone to infections and bruising or bleeding. Other side effects include hair loss, loss of taste and neuropathy, which may manifest itself as a feeling of 'pins and needles'. Your doctor will explain the side effects for your particular chemotherapy regime.

HORMONE THERAPY

To grow, prostate cancer needs the male hormone 'testosterone'. When the cancer has spread beyond the prostate to nearby glands or bones ('metastasised'), its growth can be delayed by stopping testosterone from reaching it. This is called 'hormone therapy'.

There are three types of hormone therapy for advanced prostate cancer:

Injections of drugs called 'LHRH agonists' (see page 26)

Anti-androgen drug therapy (see page 26)

Surgical removal of the testicles (called 'orchidectomy')

ORCHIDECTOMY

Orchidectomy is not a common treatment for prostate cancer. It involves removing the testicles by surgery. LHRH agonist injection treatment is as effective as an orchidectomy operation, and much more common.

Scan the QR code to learn more information on chemotherapy



PALLIATIVE CARE

Palliative care is sometimes called supportive care. It is usually offered to people who have a life-limiting illness. A life-limiting illness is one that will shorten a person's life but it may still mean that they continue to live an active life for many years. Palliative therapy does not stop the growth of the cancer, but aims to reduce the pain and any other problems caused by it. It is very important that your GP and hospital team are aware of any other medication you are taking. This includes any herbal or 'alternative' remedies. If you wish to try complementary therapies to help you cope with your symptoms, you should always talk to your own doctor first. They will advise you whether they are safe.



Learn more about palliative care

OTHER TREATMENT

Tablets containing steroid drugs can be effective but may cause stomach ulcers and fluid retention. Other medication can reduce these side effects.

Bisphosphonates

At this stage of the disease, your doctor may recommend medicine that helps prevent thinning of the bones.



Radium-223

Radium-223 is a radioactive medicine used for people who have prostate cancer that has spread to the bones. It can help to control bone pain and allow some prostate cancer patients to live longer. You can have radium-223 if you have advanced prostate cancer and:



Learn more about radium-223

- Your prostate cancer has grown even when you have been treated with hormone therapy (hormone- or castrate-resistant prostate cancer)
- Your prostate cancer has spread to the bones and is causing pain
- You have already had or are unable to have chemotherapy or other types of treatment
- You have healthy bone marrow (the spongy substance inside bones that helps to make some blood cells).

It is given as an injection in the back of your hand. You will usually have six treatments.



Olaparib (Lynparza)

Olaparib is a medicine used to treat certain types of prostate cancer that have spread to other parts of the body. You can have olaparib if you have advanced prostate cancer and:



Learn more about Olaparib (Lynparza)

- You have castrate-resistant prostate cancer
- You have changes (mutations) in either of the BRCA genes (the BRCA 1 or BRCA 2 gene)
- You live in England, Scotland or Wales. It is not currently available in Northern Ireland.

Olaparib is taken as a tablet. You take two tablets, twice a day, usually 12 hours apart.

SECTION NINE

What are clinical trials?

Clinical trials are medical research studies that may involve patients, healthy participants or both.



The aim of clinical trials is to test new treatments and answer the following questions:

Is the treatment/procedure safe?

Does it work better than the current standard treatment?

Are there any side effects?

What is the best dose to give?

Does it have an impact on quality of life?

ARE CLINICAL TRIALS SAFE?

Before any new treatment is tested in a clinical trial, it is tested by researchers in the laboratory. If it passes lab testing, it will then proceed to clinical trials. Before

the trial can begin, the trial plan must be reviewed by doctors and approved by an ethics committee. You will be monitored carefully throughout the study to ensure that any issues are identified as soon as possible.

The researchers should ensure that you understand what the trial involves and the potential side effects and risks. You will be asked to give your consent before you can take part. More information on consenting to treatment can be found on page 13.

Should you change your mind, you are able to leave the trial at any time.

Visit the infopool for more information on clinical trials, including frequently asked questions and common myths



TOP 5 THINGS YOU NEED TO KNOW ABOUT CLINICAL TRIALS



Placebo

A placebo is a dummy treatment. It is often designed to look the same as the trial treatment. But it is not 'active'. It is sometimes called a sugar pill. Researchers use a placebo to find out whether the new treatment works better than doing nothing at all. People with cancer only get a placebo:

- **Alongside a standard treatment. In the case of prostate cancer, this may include active surveillance.**
- **If no standard treatment is available for their type of treatment. So they are not losing out on treatment.**



Randomised control trials

Randomised control trials compare two or more different groups of patients. There is usually a:

- **Control group who get the standard treatment of placebo, and**



A patient's voice

'Taking part in research like clinical trials is important for Black men. Not only does it offer the chance to access the latest treatments but unless we take part now the medicines of the future may not be suitable for our sons and grandsons.'

Alfred – *clinical trial participant*

- **A treatment group who get the new treatment.**

Randomisation is when people are put into either one of these groups by chance. A computer randomly decides which group you are in. Randomisation is the best way of making sure that the results of trials are free from bias.

Clinical trials are divided into four main stages or phases:

1 Phase 1 trials test the safety and side effects of a new treatment and investigate the best dose to use. They are usually very small with around 20 to 50 people taking part.

2 Phase 2 trials continue to investigate the safety, side effects and dosing, but also start to look at how well the new treatment works. They can involve more than 100 participants.

3 Phase 3 trials compare the new treatment to the current standard treatment. Researchers also continue to investigate the safety and side effects. These trials often recruit hundreds or thousands of people.

4 Phase 4 trials take place after the new treatment has been licensed and is being used by the general public. Data on the safety, efficacy, side effects, long-term risks and benefits is collected.



Blinded trials

Blinded trials are where only the researchers know who is getting the new treatment or the standard treatment (control). As a patient, you will not know. In double-blinded trials, no one knows which group you are in.



Eligibility criteria

This is a set of conditions (criteria) that must be met for someone to take part in a clinical trial. They make sure people taking part in a trial are as similar as possible in terms of things like type and stage of disease, age, sex, ethnicity and treatment history. This allows researchers to see if any results are because of the new treatment or something else. Criteria will differ from study to study.



Informed consent

Everyone taking part in a clinical trial must give their informed consent to take part. It must be given voluntarily. Before giving your consent someone will tell you about:

- **The purpose of the trial**
- **The length of your involvement**
- **What is expected of you**
- **Any treatments, interventions or tests you will have**
- **Any possible risks of taking part**
- **Who to contact if you have questions.**

Before making your final decision, you should make sure you understand everything you have been told. If you are not clear, do not be afraid to ask questions.

Once you are confident you understand what the trial involves for you and you're happy to take part, you can sign the consent form. Even when you have done this, you can still leave the trial at any time.



A patient's voice

'If you ... get offered a clinical trial, I'd say do it and it's going to help other people in the future, it may help you directly doing the trial...the additional engagement with your healthcare professionals that being on a trial gives you is beneficial to your mental health.'

Dave – *clinical trial participant*

HOW DO I JOIN A CLINICAL TRIAL?

If you are interested in joining a clinical trial, speak to your doctor or nurse. You can also find details of current clinical trials using the clinical trial finder on the infopool. Just add in a few simple details about your prostate cancer and you can search for trials that are suitable for you.

For more information on clinical trials, visit the infopool. You can also find details of current clinical trials using our clinical trial finder



SECTION TEN

What will be the impact on my emotions and wellbeing?

Living with prostate cancer is likely to have an impact on your emotional wellbeing as well as your physical health.

There is no right or wrong way to feel after a cancer diagnosis. Many people experience a wide range of different emotions including shock, fear, guilt, anger and sadness.

Diagnosis and treatment of prostate cancer can lead to a shift in your sense of identity, which can be difficult to deal with. For example, you may be unable to work or may experience physical changes that affect your body image. It can also be an isolating experience and you may feel that those around you don't understand.

These feelings are completely normal and they may continue or change over time. However, if you are experiencing symptoms of anxiety or depression, it is very important to speak to your GP and seek professional help. Symptoms of depression include:

- **Feeling low or sad for most of the time**
- **Feeling hopeless**
- **Losing interest in things that you usually enjoy**
- **Changes in appetite, sleeping patterns and concentration**
- **Having suicidal thoughts or feelings of harming yourself.**



HOW CAN I LOOK AFTER MY EMOTIONAL WELLBEING?

Here are five top tips to help you to manage your emotional wellbeing.

- **Talk about how you feel.** You can talk to people that you know well and trust such as friends and family. Some people find it easier to talk to someone they don't know; your doctor or nurse may be able to refer you to a counsellor who can help you.
- **Join a local support group.** They provide valuable support and information. They can also offer a safe space to ask questions, share your experiences and listen to others in a similar situation.
- **Eat well.** Eating a healthy, balanced diet can increase your energy levels and help to improve your mood.
- **Physical activity.** Exercising and taking part in physical activity can increase your energy levels, improve your mood and help to manage stress. It is important that you do not push yourself too hard as many treatments for prostate cancer may affect your ability to exercise. Even

Visit our 'emotional and psychological support' page on the infopool, where you can find information and resources to help manage your mental health.



gentle exercise such as a short walk or walking up the stairs can help to improve your emotional wellbeing.

- **Take time for yourself.** Spending time doing things that you enjoy, whether that be drawing, gardening or watching TV, can give you something more positive to focus on. Some people also find relaxation techniques such as meditation or yoga help them to feel better.



GETTING SUPPORT FOR YOUR EMOTIONAL HEALTH

Talking therapies

These are free and are delivered by fully trained and accredited NHS practitioners. They can help with stress, anxiety and depression. In England, Scotland and Wales you can refer yourself directly to an NHS talking therapies service without a referral from a GP or your GP can refer you. In Northern Ireland, you need to visit your GP first.

Cancer psychology service

Some hospitals will have a cancer psychology service. These are made up of clinical psychologists or specialist counsellors. Ask your healthcare team for more information.

Cancer charities and hospice

These often offer emotional support either face-to-face or via the phone or internet.



For contact details of support groups and other useful organisations, please see page 44.



A patient's voice

'Do the things you like to do. I am a musician, so I spend time in music, and it helps alleviate these emotional side effects... Keeping things that would remind you of yourself, watching your diet on a practical level and exercising more to help restore body image.'

Michael – *hormone therapy and chemotherapy*



A patient's voice

'I would certainly advise reading as much material on the side effects and treatments as possible because you don't always get all the detail during consultations. It's very important you take as much ownership as possible.'

Alan – *hormone therapy injections*

SECTION ELEVEN

What happens after treatment?

After treatment ends, you will be seen by your GP and hospital team to monitor your health and to manage side effects.

Find out which diagnostic services, treatments and support options are available in hospitals near you by visiting our local services tool on the infopool



ONGOING SUPPORT

You may be relieved when your treatment is finished, but you may also feel worried that you no longer have regular hospital appointments. However, you may be assigned a key worker who will continue to support you after your treatment. If not, ask your hospital team about contact details for someone you can speak to if you have further questions. You will have follow-up appointments and check-ups afterwards. Your hospital may have a peer support group, which you are welcome to continue to attend, and you will always be able to contact your GP with questions. For more places you can find support, see page 44.

FOLLOW-UP APPOINTMENTS

After your treatment, you will have follow-up appointments at either your hospital or with your GP. Where these take place, how many

appointments you attend and how often you are invited to follow-up appointments will depend on your own individual experience of cancer. It is important that you attend your follow-up appointments. Your GP or one of your specialist team will use them to check how your cancer has responded to treatment and will discuss your side effects. You should also use these appointments to ask any questions you may have.

You may find it helpful to:

- **Take notes, and to bring the notes you took at the last appointment to the next one**
- **Ask the doctor to write something down for you**
- **Take your partner or friend with you**
- **Ask to record the appointment – for example, on your mobile phone**
- **Ask the same question again if it wasn't explained in a way you understood the first time.**



You will also continue to have PSA tests regularly after your treatment is finished. These allow your care team to monitor your cancer to see if you may need more treatment in the future.

SECTION TWELVE

How can I use my experience to help improve prostate cancer care?



Watch a short video
on Prostate Progress



A patient's voice

'The more information and support that PCR receive the quicker they can find a solution to this life changing cancer.'

Paul – *Prostate cancer patient and supporter of Prostate Progress.*

WHAT IS PROSTATE PROGRESS?

Prostate Progress is a first-of-its-kind data platform developed by Prostate Cancer Research in collaboration with the NHS. It has been co-designed and overseen by patients. It is dedicated to finding an early test, improving treatments and ultimately, saving lives.



What do I have to do?

- Go online and complete a simple registration process.
- Fill in some questionnaires about your prostate cancer and general health.
- A few times a year you will be emailed to come back and complete more questionnaires to see how your health is changing over time.



Who can take part?

Anyone in the UK who has ever been diagnosed with prostate cancer. You can take part using a phone, computer or tablet.



What are the benefits of taking part?

- You will provide vital evidence to help researchers find new ways to prevent, detect and treat prostate cancer.
- You will be able to see the information you contribute over time and compare your experience to that of others.
- You can learn about new clinical trials and research you may be able to take part in.



Join thousands of others and
sign up to prostate progress

www.ProstateProgress.org

Powered by

NHS DATA

SECTION THIRTEEN

How to access and make use of side effects support

People often struggle to find support to manage their side effects.

The National Institute for Health and Care Excellence (NICE) has put together guidelines for the diagnosis and management of prostate cancer. These are not a legal requirement, but you can use this information to ask questions of your healthcare team.



GETTING SUPPORT FOR PEEING PROBLEMS

NICE say that if you are having problems peeing your healthcare team should:

1. Offer you access to a specialist continence service for assessment, diagnosis and treatment. This could include: coping strategies, pelvic floor exercises, bladder retraining or medicines and tablets.
2. Offer you a referral to a specialist surgeon (urologist) who can talk about surgical options. This is usually only done if other strategies have not worked.

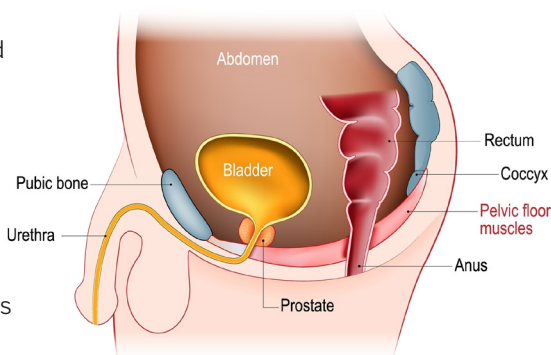
What can I do to help myself?

The pelvic floor is important in bladder control and helping to keep an erection.

Visit our 'dealing with peeing problems' page on the infopool, where you can find more information and resources.



Pelvic floor exercises can help to strengthen these muscles. If you need support you can be referred to a pelvic health physiotherapist.



GETTING SUPPORT FOR SEXUAL ISSUES

Some treatments for prostate cancer will cause problems with sexual function, e.g. getting or keeping an erection (erectile dysfunction).

What do NICE say about sexual issues?

NICE say that your healthcare team should offer:

1. Access to a specialist sexual dysfunction service.
2. PDE5 inhibitors (e.g. Viagra or Cialis) to improve the chance of spontaneous erections.
3. A vacuum erection device (VED) if PDE5 inhibitors do not work.

4. Alprostadil to increase blood flow to your penis. It comes as a cream, pellet or injection. You will usually need to try the VED first.

5. An opportunity to talk to a psychosexual therapist.

For more information, access our 'getting support for sexual problems' page on the infopool.



LATE EFFECTS RADIOTHERAPY

Late effects of radiotherapy can be:

- New side effects that start 3-6 months or more after your radiotherapy has ended.
- Early side effects that carry on for more than three months after radiotherapy has ended.

Where do I go to get help?

The first step is to talk to your GP or healthcare team. It is a good idea to keep a diary of your symptoms beforehand. They may then:

- Prescribe treatments - this will depend on your symptoms.
- Refer you to specialist services such as the continence service, late effects service, gastroenterology service or sexual dysfunction service.

Scan the QR code to get access to our 'late effects of radiotherapy' page on the infopool.



HOT SWEATS AND FATIGUE

Hot sweats

Hormone therapy blocks or lowers the amount of the male sex hormone testosterone. This causes hot sweats.

Where do I go to get help?

Your GP can offer you medications like medroxyprogesterone (Provera) or cyproterone acetate (Cyprostat).

5 top tips to manage your hot sweats

- Wear light clothes made of natural fibres.
- Dress in layers.
- Sip water throughout the day.
- Cut down on alcohol and caffeine.
- Try to avoid stress.



Fatigue

Fatigue is a feeling of extreme tiredness that doesn't get better after sleep or rest. It is caused by low levels of testosterone, disrupted sleep because of hot sweats or mild anaemia (fewer red blood cells than normal).

5 top tips to manage fatigue

- Go for a walk or take other gentle exercise.
- Pace yourself - stop before you feel tired.
- Keep your normal sleep routine.
- Learn some relaxation techniques.
- Join a fatigue education course.

Scan the QR code to access our 'managing hot sweats and fatigue after hormone therapy' page on the infopool.



SECTION FOURTEEN

Partners and carers

Carers and partners of people with prostate cancer are also impacted. Read some tips to help manage your own physical and emotional health.



A partner's voice

'You need to carry on planning holidays and treats. Separate beds can enable you to get more sleep... counselling can help you come to terms with the profound changes that testosterone deprivation brings about... Relationships often become deeper and more affectionate once sex drive has vanished...'

Sue – partner treated with hormone therapy. Listen to Sue's story: <https://www.theinfopool.co.uk/story/sues-story>



THE IMPACT ON PARTNERS AND CARERS

Hearing that your partner or someone you care about has cancer is challenging and stressful. Many partners put their own needs and feelings to one side to focus on the person with cancer. Doing this over a long period of time is not good for your health and wellbeing and can result in fatigue, sleep problems, anxiety, stress and headaches.



10 TOP TIPS TO HELP LOOK AFTER YOUR PHYSICAL AND EMOTIONAL HEALTH

- 1 Take time out for yourself.** Taking 15–30 minutes per day just to relax can be beneficial. You can take a short nap, go for a walk or read a book.
- 2 Don't neglect your personal life.** Remain connected with friends and family and keep up your own personal interests. This may be a gym class or reading group.
- 3 Don't be afraid to talk about how you feel.** Be honest about your feelings. It's OK to feel annoyed or irritated at your partner or what's happening in your life. Share how you feel with someone you trust. You can also join a support group.
- 4 Learn some relaxation techniques.** Deep breathing, mindfulness and meditation can help.
- 5 Look after your physical health.** If you're aged between 40 and 74, you may be entitled to a free NHS health check. Ask at your GP surgery. Make sure you take advantage of all NHS screening tests offered to you.

6 Make sure you eat properly. Eating healthily and regularly will help keep your immune system in good working order and your energy levels up.

7 Get plenty of sleep. Make sure your bedroom is at the right temperature. Cooler conditions can be better for sleeping. Try not to look at phone or tablet screens for about one hour before bed. They make you too alert psychologically and physically.

8 Spend quality time with your partner. It's important to set aside some time to do enjoyable things together. Maybe plan a date night, go to the cinema, enjoy a walk in the park or visit a café.

9 Learn more about prostate cancer and its treatments. This can help you feel more involved in your partner's care.

10 Don't be afraid to ask for help. Your workplace and your GP practice can provide support to help you manage everyday stresses.



SEX, INTIMACY AND RELATIONSHIPS

Dealing with a prostate cancer diagnosis can put a strain on your relationship. In addition, some treatments have side effects that can cause a loss of libido, erectile dysfunction, penile shrinkage and dry ejaculations. These can affect your partner's self/body esteem and feelings of masculinity.

Visit our dedicated partners and carers page on the infopool to find useful resources and stories from other partners and carers.



WHAT CAN YOU DO TO HELP?

- **Keep communication open and honest**
Good communication is important to keep your relationship working well.
- **Make changes to your sex life** Reaching acceptance that things may not be the same as before is important. This doesn't mean your sex life won't be as good as before, just different!
- **Visit a psychosexual and relationship therapist for support with any issues**
You may be able to access this service via the NHS. Speak to your GP or hospital team.
- **Focus on intimacy instead of penetrative sex** Intimacy is a feeling of closeness, togetherness and emotional connection with your partner. Exploring love and intimacy in non-sexual ways might include mutual massage, kissing and cuddling, holding hands, having fun together and giving little inexpensive gifts.

A partner's voice

'It's difficult being a partner...I want to look after him but likewise, I know that I also need to look after myself...how can I protect the children? Sometimes you need sadly, people who have been through that or are going through that because they will understand you and I will understand them ...'

Gail – partner treated with hormone therapy and chemotherapy. They have four children. Listen to Gails story: <https://www.theinfopool.co.uk/story/gails-story>



Your most important resources are your GP and hospital team. They know your medical history and are best placed to advise you.

Where can I get help and support?



The infopool (www.theinfopool.co.uk) has information on testing and diagnosis, choosing a treatment, living with side effects, palliative and end-of-life care and how to join a clinical trial. Importantly, you can access hundreds of stories from others who have been affected by prostate cancer, including their partners and carers.



Find a prostate cancer support group

Tackle Prostate Cancer support patient groups around the UK. You can search for local or online groups on their support group page.

Helpline: 0800 035 5302

9am–9pm, 365 days a year



Access to a nurse or support line



Cancer Research UK

Helpline: 0808 800 4040

9am–5pm, Monday–Friday



Macmillan Cancer Support

Helpline: 0808 808 0000

8am–8pm, Monday–Friday



Prostate Cancer UK

Helpline: 0800 074 8383

9am–5pm, Monday–Friday (Wednesday: 10am–5pm)



Resources for carers



Carers UK

If you have a question about caring or just want to talk to someone, you can call their helpline: 0808 808 7777

9am–6pm, Monday–Friday



National Prostate Cancer Partners Support Group

Meets quarterly via Zoom.

Visit Tackle Prostate Cancer for more information.

About us

Prostate Cancer Research (originally the Prostate Cancer Research Centre) was founded in 1988 with the objective of finding innovative treatments to stop prostate cancer in its tracks.

It is only through research that we can build a future in which no family will have to fear losing a loved one to prostate cancer. But we're not just here to add years to life; we're also about adding life to years. Our vision is a world where people are free from the impact of prostate cancer.

Our mission is that together, we will develop and deliver breakthrough medicines and treatments. We only fund research, and we prioritise maintaining a deep understanding of the needs and perspectives of patients and their families.

If you would like to receive updates on our research and fundraising, plus the latest prostate cancer research developments, please complete and return the enclosed form.



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Transforming research.
Transforming lives.



“ Make sure you get as much information as possible. Talk to people who may be able to help. Seek emotional support from friends and family if you want to talk about your condition. Follow advice from your medical team. Try not to bury your head in the sand. Try to live an active life instead of putting your life on hold...be patient, recovery takes time...speak to your partner about your feelings and concerns...”

Herman – *active surveillance and radical prostatectomy*

Share your story on the infopool and help others to make better informed choices

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