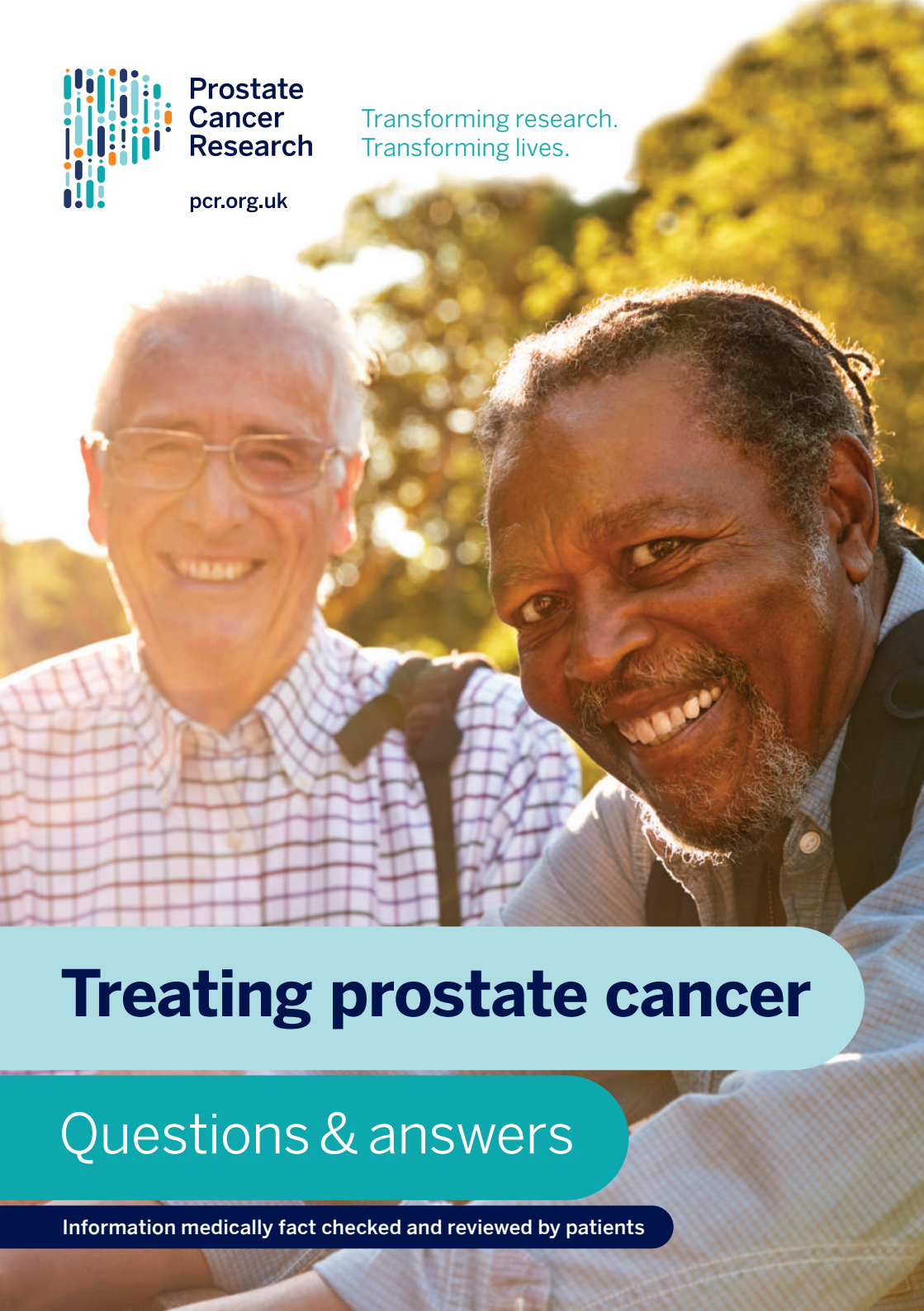




**Prostate
Cancer
Research**

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Transforming lives.



Treating prostate cancer

Questions & answers

Information medically fact checked and reviewed by patients

Why we have created this booklet

Every year more than 47,500 men in the UK are 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 or a loved one are given. This booklet aims to give you an insight into the disease and current treatments in an easily digestible question-and-answer format.



How can I use this booklet?

CONTENTS

- 02 **Section one**
What is prostate cancer and how is it diagnosed?
- 08 **Section two**
How is early prostate cancer treated?
- 10 **Section three**
Radical prostatectomy – what is involved and what are the risks?
- 16 **Section four**
Radical radiotherapy – what is involved and what are the risks?
- 23 **Section five**
Locally advanced prostate cancer – what is it and how is it treated?
- 26 **Section six**
Late or advanced prostate cancer – what is it and how is it treated?
- 29 **Section seven**
What are clinical trials?
- 32 **Section eight**
What will the impact be on my emotions and wellbeing?
- 34 **Section nine**
What happens after treatment?
- 36 What if I have questions or comments?

We have designed this booklet 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.

There are several treatments for cancer of the prostate, 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.

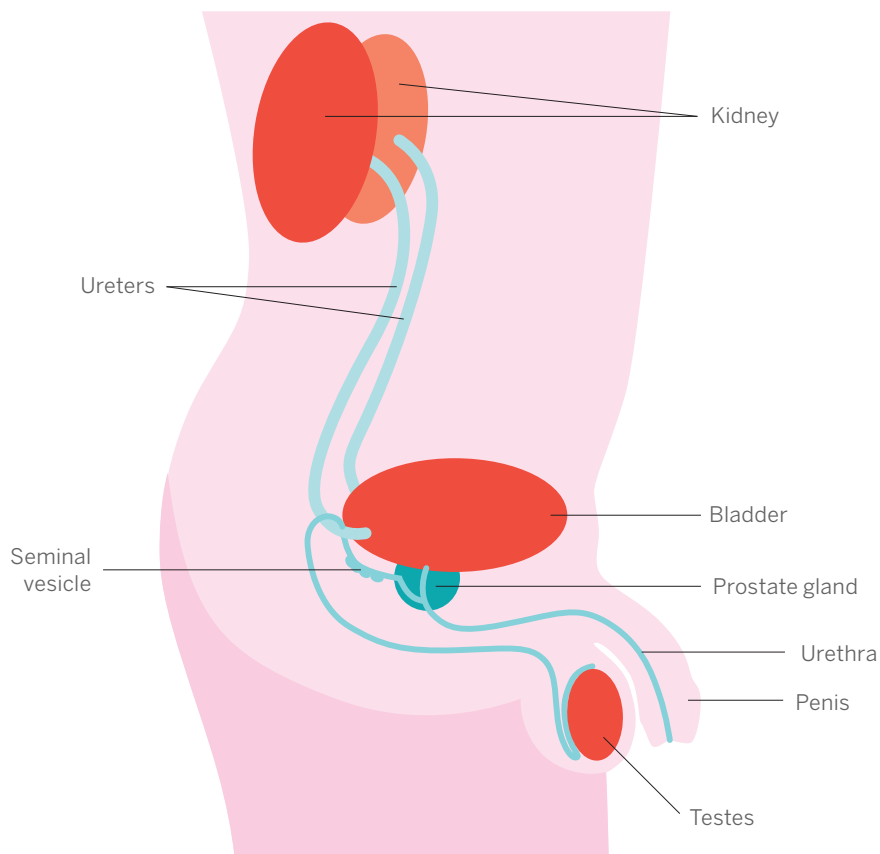
We have included a tear out page with a list of suggested questions for you to ask your medical team and space for notes.

Relatives and friends may also find this booklet useful.

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

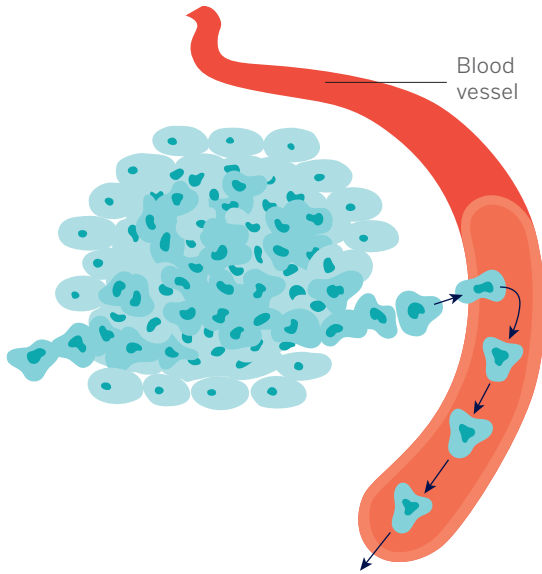
SECTION ONE

What is prostate cancer and how is it diagnosed?



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) to relieve the symptoms of BPH.

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.

Around one in eight men will get prostate cancer at some point in their life. This risk rises to one in four for Black men. 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 factors** There is some evidence that obesity and diet has an effect.

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.

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.

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 it 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.

For those aged between 50 and 69, a PSA level of above 3 nanograms per millilitre is considered raised. However, 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 necessarily mean you have cancer, nor does a lower level mean you do not.

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.

FURTHER TESTS

Your GP will ask you to describe how you feel. Depending on the results of the digital rectal examination, 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 prostate cancer is detected, 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 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 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.

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. A score of 1 means you are very unlikely to have prostate cancer whereas a score of 5 means that you are highly likely to have prostate cancer. You could also be given a PI-RADS score, which uses a similar 1-to-5 scoring system.

Biopsy and trans-rectal ultrasound and biopsy (TRUS)

You will be asked to lie on your side with your knees drawn up towards your chin (the same as for a DRE described on page 4). An ultrasound probe is inserted in your back passage. A needle is used to take samples (biopsies) from your prostate, and these are sent for examination under a microscope to look for prostate cancer. Usually 10 or more biopsies are taken and you will have a local anaesthetic to make the procedure more comfortable for you. Another method of obtaining prostate samples is through the perineum. This is called transperineal biopsy. It is usually done under sedation or general anaesthetic. Many patients will also receive 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.

You may also have a CT scan or MRI scan (see page 17). These help to tell the difference between early and late prostate cancer.

CANCER AGGRESSIVENESS (GLEASON SCORE)

The biopsy is used to produce your Gleason Score. Prostate cancer tissue can look like normal prostate tissue – the extent to which the cancer tissue looks like normal tissue is called the cancer grade.

Low-grade cancer looks most like normal tissue and high-grade cancer looks least like normal tissue. In general, the lower the grade, the less aggressive the cancer and the less likely it is to shorten life expectancy.

For prostate cancer, the Gleason grading system is normally used. Grade 3 is the least aggressive and 5 is the most aggressive. Because prostate cancer is very variable in appearance, the first grade is given to the most frequent appearance and the second grade to the second most frequent appearance under the microscope.

The two Gleason grades are then added together to give the Gleason Score, which ranges from 6–10.

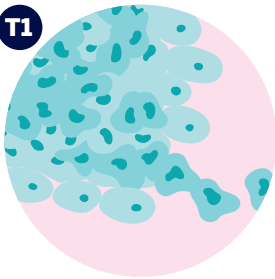
Grade Group	Gleason Score	Risk
1	6 (3+3)	Low
2	7 (3+4)	Medium
3	7 (4+3)	Medium
4	8 (3+5), 8 (4+4), 8 (5+3)	High
5	9 (4+5), 9 (5+4), 10 (5+5)	High

CANCER STAGING: HOW FAR HAS THE CANCER SPREAD?

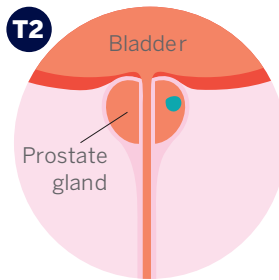
Prostate cancer is described as 'localised', 'locally advanced' disease or 'advanced'. It starts with changes in the cells of the prostate. The cells form a lump that may eventually be felt in a physical examination.

Surgeons describe how far the cancer has spread according to 'TNM stages', standing for primary Tumour, Nodes and Metastasis. The T stage tells you the size of the tumour and is usually detected using a DRE or an MRI scan. The N stage tells you whether the cancer has spread to the lymph nodes and is usually detected using an MRI or CT scan. 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 and it is usually detected using a bone scan. Metastasis can be M0 (negative) or M1 (positive). M1 indicates that the cancer has spread to other parts of the body.

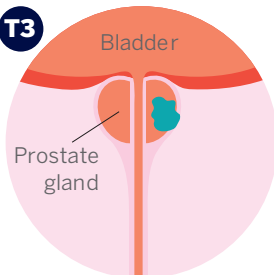
Around 60% of patients are diagnosed with early disease and 40% are diagnosed at a later stage. However, even when prostate cancer has reached the late stage, it may still be possible to slow down its growth. We discuss this in detail in Section Six.

T1**T1 stage**

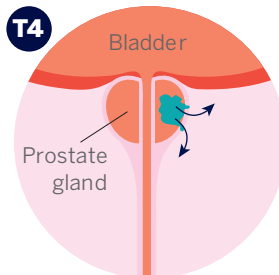
Early prostate cancer that can only be seen under the microscope.

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.

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:

- 1 Monitoring**
Through active surveillance or watchful waiting
- 2 Radical prostatectomy**
Find more information in Section Three
- 3 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, it may be best to observe your cancer, rather than begin treatment, to 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.

What is watchful waiting?

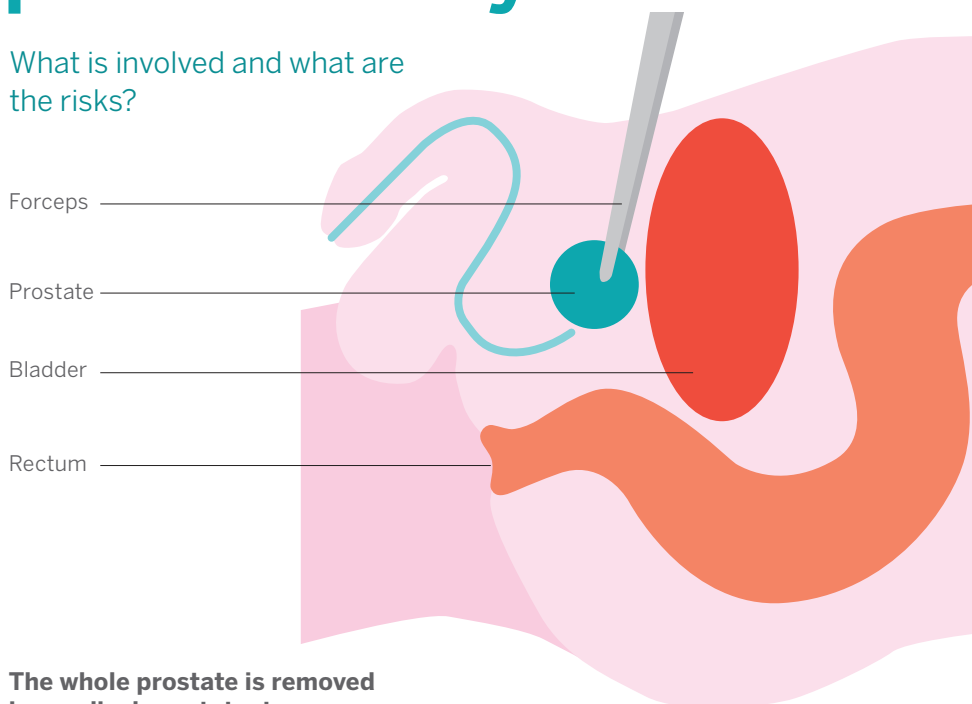
Watchful waiting also involves check-ups to monitor the prostate cancer but these do not usually involve DRE and biopsies. It is often the best option for those who won't benefit from treatment or those whose cancer won't cause problems during their lifetime.



SECTION THREE

Radical prostatectomy

What is involved and what are the risks?



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.

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.

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.

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.

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.
- **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.

There are treatments 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.

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.

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 2-4 days for laparoscopic and open surgery, or 1-2 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 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.
- **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.



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 29). **This will be your decision.**

It is important that you are aware of the side effects of treatment before you sign a consent form.



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.

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.

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.

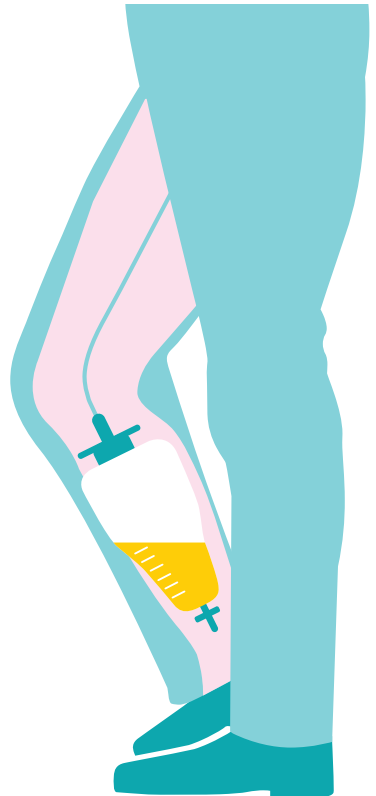


What happens when I go home?

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 OTC 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. You will be shown how to do pelvic floor exercises to improve continence. 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 after a month although you will probably still feel more tired than usual.



SECTION FOUR

Radical radiotherapy

What is involved and what are the risks?

Radical radiotherapy is another treatment for prostate cancer. It 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 RADIO THERAPY

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 before surgery (neo-adjuvant radiotherapy) 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 is 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 one further visit 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. You may be asked to drink some water before each therapy as this will fill your bladder and reduce the amount of bladder tissue in the radiotherapy beam.

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 23) before radiotherapy to shrink the prostate, and maybe afterwards for some months.

OTHER TYPES OF EXTERNAL BEAM RADIOTHERAPY

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.

Stereotactic body radioation therapy (SBRT)

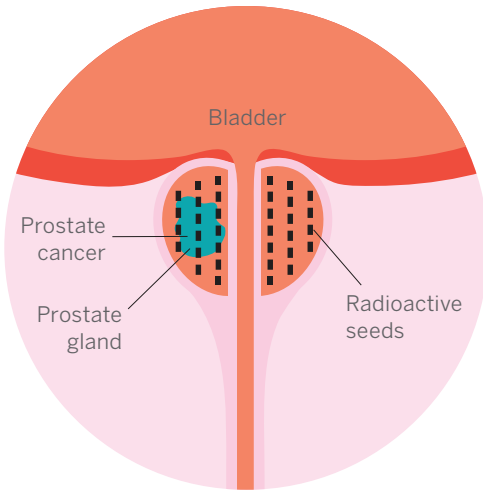
SBRT uses advanced image-guided techniques to provide large doses of radiation to a precise area. Since there are large doses of radiation in each dose, the entire course of treatment is given over a few days. SBRT is often known by the trade names of the machines that deliver the radiation, such as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

There are other forms of external beam radiotherapy available as part of clinical trials (page 29).

BRACHYTHERAPY

This form of radiotherapy can be given in two ways:

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



Radioactive seeds or rods are placed in the prostate and destroy the cancer over a period of time.

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 to the left). It can also be effective for some immediate or high-risk patients. 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.

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.

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 23) 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 scan) 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 discuss any questions or 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, which is the removal of your prostate gland and surrounding tissues.

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 mucous (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 bowels, always tell your doctor so they can check it out.

- **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 there is a delay, and semen comes out after you orgasm.
- **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.

SECTION FIVE



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.

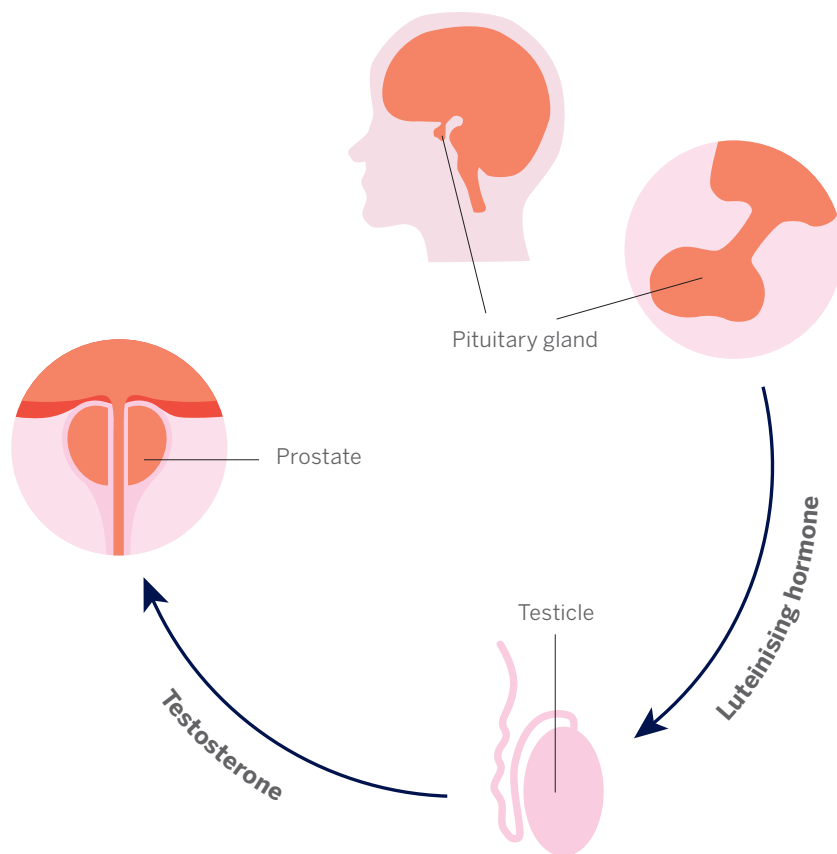
You may be offered radiotherapy treatment to include the surrounding structures (as well as the prostate), usually in combination with two to three years of hormone therapy. Hormone

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 25)
- **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 nothing to be ashamed of.

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. 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.

The first injection is usually given at the hospital, but further injections can be given by your GP. The injections are repeated every month or every three months, according to the recommendations of your doctor.

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

- You will be unable to have an erection, lose your sex drive and be infertile.
- The testes shrink and many men develop hot flushes, 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.

SECTION SIX

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 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 29).





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 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

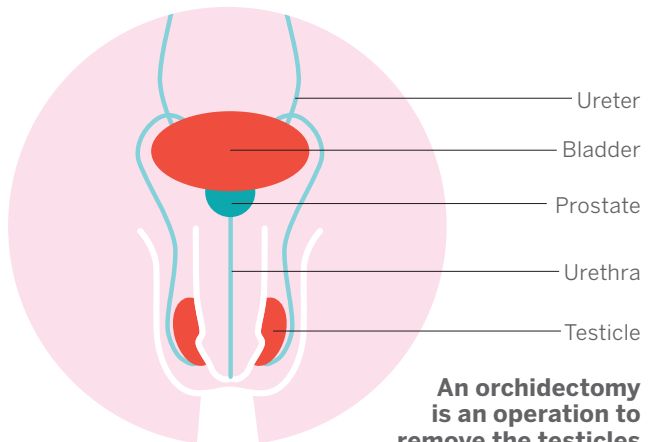
To grow, prostate cancer needs the male hormone 'testosterone'. When the cancer has spread beyond the prostate to nearby glands or bones ('metastasised'), its growth can be delayed by stopping testosterone from reaching it. This is called 'hormone therapy'.

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

• Injections of drugs called 'LHRH agonists' (see page 25)

• Anti-androgen drug therapy (see page 25)

• Surgical removal of the testicles (called 'orchidectomy')



An orchidectomy is an operation to remove the testicles

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.

Side effects of an orchidectomy

Because an orchidectomy cannot be reversed, you must consider the following permanent side effects before you give your permission.

You will:

- Lose your ability to get or maintain an erection (impotence)
- Lose your sex drive
- Be infertile
- Experience hot flushes (owing to hormonal changes)
- Be left with some of the testicle tissue: 'the shell' of the testicle. However, it will feel smaller than a normal testicle.

It is possible to have prosthetic testicles implanted either during the operation or afterwards. These can be cosmetically and psychologically beneficial for some men, but some may experience problems with them long-term.

It is important to ask about an implant and discuss it with your care team before making a decision.

PALLIATIVE CARE

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 any 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.

OTHER TREATMENT

Radiotherapy

Very effective in reducing prostate cancer pain if the cancer has spread to the bone. You may be offered Radium-223, which is a specialised form of radiotherapy for cancer that started in the prostate and spread to the bones. You may have to travel to a different hospital for it.

Tablets containing steroid drugs

Can be effective but can cause stomach ulcers and fluid retention. Other medication can reduce these side effects.

Bis-phosphonates

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

SECTION SEVEN

What are clinical trials?

A number of treatments for prostate cancer, such as cryosurgery, laser therapy and HIFU (high-intensity focused ultrasound), are available at some clinics.



Because these treatments are relatively new, not enough time has passed to know whether they are any more or less effective for early prostate cancer. You may be invited to join a clinical trial of one of these treatments.

Clinical trials are medical research studies that may involve patients, healthy participants, or both. The aim 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 before you take part in the clinical trial. 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.**

WHAT ARE THE DIFFERENT TYPES OF CLINICAL TRIAL?

There are two main types of clinical trial: interventional and observational.

Interventional studies investigate a new intervention or treatment. Those taking part are often divided into different treatment groups so that the researchers can compare the effects of different treatments.

During **observational studies** researchers observe and collect information on participants without any intervention.

Clinical trials are also divided into four main stages or phases:

- 1 Phase 1 trials** are used to test the safety and side effects of a new treatment. Researchers also investigate the best dose to use. Phase 1 trials 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 the researchers also start to look at how well the new treatment works. They are larger than phase 1 studies and 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. They are large, often recruiting hundreds or thousands of people.
- 4 Phase 4 trials** take place after the new treatment has been licensed and is being used. Researchers continue to investigate the safety, efficacy and side effects of the treatment, collecting data on the long-term risks and benefits. Phase 4 trials are large with hundreds or thousands of people taking part.

What are randomised clinical trials?

Nearly all phase 3 trials and some phase 2 trials are randomised. This means that the people taking part in the trial are put into different treatment groups at random. Randomised trials have two or more different treatment groups. There is usually a control group, which has the standard treatment. The other group receive the new treatment or procedure that is being tested.

Randomised trials help the scientists to ensure that the results from the trial are reliable and not biased. For example, researchers may put healthier participants into a particular group without realising. These participants are likely to have better outcomes than those who are more unwell so it may make it seem like a particular treatment works better than it does.

What is the placebo effect?

Many people feel better if they receive a fake treatment, known as a placebo, simply because they believe it will have a positive effect. This is known as the placebo effect. In order to make sure a treatment is actually working, the control group may be given a placebo. Participants would only be given a placebo if it is either given alongside standard treatment or if there is no standard treatment available. If there is no standard treatment, those given the placebo would not receive treatment if they were not taking part in the trial, so the trial does not put them at a disadvantage. It would be unethical to withhold cancer treatment from people who need it so regardless of whether you receive the new treatment, you will always be given the best available treatment and care.

To reduce the placebo effect, trials may be blinded or double-blinded. In blind trials, you do not know whether you have been given the new treatment or not. In double-blind trials, neither you nor the doctor administering the treatment knows whether you have been given the new treatment.

SHOULD I TAKE PART IN A CLINICAL TRIAL?

Deciding whether or not to take part in a clinical trial is a personal decision, and there is no right or wrong answer.

Clinical trials help doctors find new ways to treat prostate cancer which could help others affected by the disease in the future. Taking part in a trial may mean that you receive more regular checks and support and it may also enable you to access and benefit from new cutting-edge treatment.

However, there is no guarantee that you will be given the new treatment as you may be placed in the control group. There is also the possibility that the new treatment does not work better than the current standard treatment and there may be unforeseen side effects.

HOW DO I JOIN A CLINICAL TRIAL?

If you are interested in joining a clinical trial, the best person to speak to is your doctor or nurse. They will be able to discuss any trials that may be suitable for you to join. If appropriate, they will be able to contact a doctor involved in the trial and refer you.

You can also find details of current clinical trials via Cancer Research UK's clinical trial database cancerresearchuk.org/about-cancer/find-a-clinical-trial

or the Be Part of Research database bepartofresearch.nihr.ac.uk



What will the impact be 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 and 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 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?

The following suggestions may help you to look after your emotional wellbeing while living with prostate cancer. It is important to remember that different things will work for different people, so don't be too hard on yourself if you find some of these steps difficult.

- **Talk about how you feel** It can be difficult to talk about how you feel but it can help your emotional wellbeing. 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 to deal with the emotional impact of prostate cancer.
- **Join a local support group** Support groups offer valuable support and information. They offer a safe space to ask questions, share your experiences and listen to others in a similar situation. This can help you to understand your own emotions and realise that you are not alone.
- **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 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.



For more information and contact details for support groups and other useful organisations, please see page 36.

SECTION NINE

What happens after treatment?

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 will be assigned a key worker who will continue to support you after your treatment, and 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 36.

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

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 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



LONG-TERM SIDE EFFECTS

Some of the side effects of prostate cancer treatment are long-term. However, most men who have had prostate cancer can expect to enjoy a good quality of life after their treatment. Incontinence issues usually improve significantly after treatment. Unfortunately, many men will continue to have problems with erections longer-term. The exact side effects depend on a number of factors, such as how your individual cancer behaved and the treatment that you have had. You should keep the information you received about your treatment, including this booklet, so you can refer back to it later if you need to. You should also not be shy about asking your GP or key worker about your side effects as new treatments may become available that will help you manage them.

What if I have questions or comments?



Your most important resources are your GP and your hospital team.

They know about your medical history and are best placed to give you advice.

This booklet does not cover all the treatments for prostate cancer, but focuses on those most frequently used in the UK.

To find a prostate cancer support group or talk to a man with prostate cancer

Tackle Prostate

tackleprostate.org/find-a-support-group-near-you.php
Helpline: 0800 035 5302
(9.00am–9.00pm, 365 days a year)

To talk to a nurse

Cancer Research UK

cancerresearchuk.org/about-cancer/prostate-cancer
Helpline: 0808 800 4040
(9.00am–5.00pm, Mon–Fri)

Macmillan

macmillan.org.uk/cancer-information-and-support/prostate-cancer#163034
Helpline: 0808 808 0000
(8.00am–8.00pm, Mon–Fri)

Prostate Cancer UK

prostatecanceruk.org/get-support/our-specialist-nurses
Helpline: 0800 074 8383
(9.00am–6.00pm, Mon–Fri, 10am–8.00pm, Wed)

For information on diet and eating well with cancer

Your GP or hospital team should be able to put you in touch with a dietitian, and they will be the best person to advise you.

For finance, benefits and work advice

Macmillan

macmillan.org.uk/cancer-information-and-support
Helpline: 0808 808 0000
(8.00am–8.00pm, Mon–Fri)

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 lives.

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“It is a privilege to be involved in the selection process for the funding of new projects. For men like me and for our nearest and dearest, it is essential that scientists are able to carry out the work of finding new ways to treat this potentially devastating disease. Treatments for prostate cancer have advanced at a phenomenal rate over the last few years.”

David Matheson
PCR Patient Representative

Join the patient voice group and help us to know what matters to you

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