Understanding locally advanced prostate cancer

"If a warning light came on in your car, you'd take it to the garage to get looked at. Why don't people do the same with their health? The important thing is to make the first step to seek help."

Errol, diagnosed with prostate cancer

About this booklet

This booklet is about locally advanced prostate cancer. It is for anyone who has been diagnosed with locally advanced prostate cancer. There is also information for carers, family members and friends.

The booklet explains how locally advanced prostate cancer can be treated. It also has information about emotional, practical and financial issues. We hope it helps you deal with some of the questions or feelings you may have.

This booklet does not have information about signs and symptoms or diagnosing prostate cancer. It is also not about early (localised) or advanced (metastatic) prostate cancer.

For information about these, we have other booklets:

- Tests for prostate cancer
- Understanding early (localised) prostate cancer
- Understanding advanced (metastatic) prostate cancer.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

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

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 140 to 151, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had prostate cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Errol, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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

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

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

Contents

About prostate cancer 5

Staging, grading and risk groups 19

Preparing for treatment 29

Treating locally advanced prostate cancer 41

After treatment 101

Your feelings and relationships 121

Financial support and work 127

Further information 133


our Vision is

About prostate cancer

The prostate 6

What does the prostate do? 7

What is cancer? 8

The lymphatic system 10

Locally advanced prostate cancer 12

Finding out you have locally advanced prostate cancer 15

Your data and the cancer registry 16

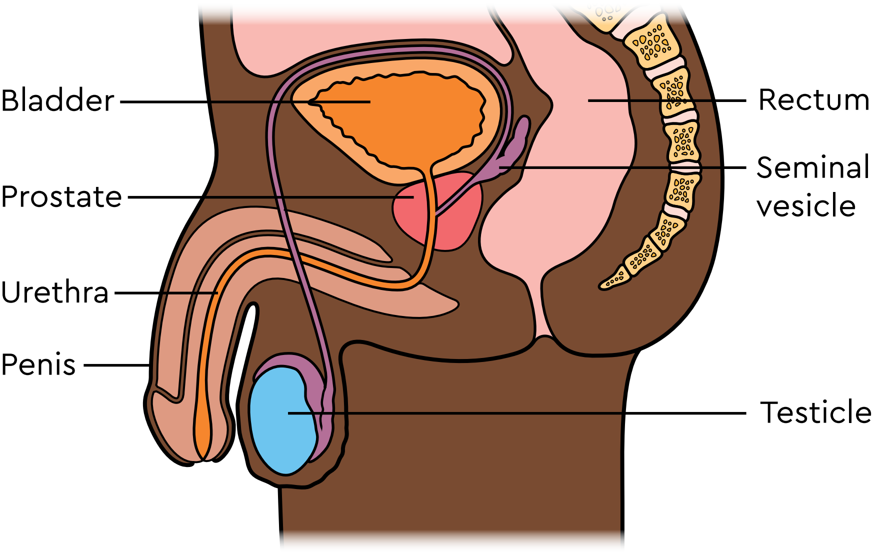
The prostate

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

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

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

The prostate



What does the prostate do?

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

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

PSA (prostate-specific antigen)

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

If you are a trans woman

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

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

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

What is cancer?

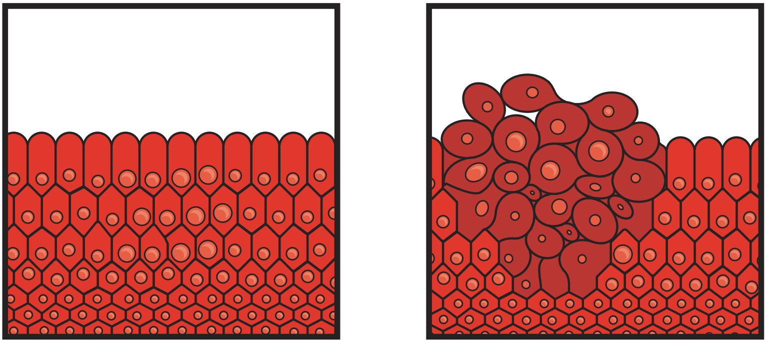
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes give the instructions the cell needs to work properly.

The genes send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body.

Cancer can spread from one place (the primary site) to another through the blood or lymphatic system. When cancer spreads and grows somewhere else, it is called a secondary cancer or metastasis.

Cancer can start in any type of cell. This includes tissue or skin cells, and cells that form the lining of the organs. It can also start in stem cells in the bone marrow. Stem cells make blood cells. Cancer that starts in stem cells does not cause a tumour. Instead, the stem cells create abnormal blood cells that behave differently from healthy blood cells.

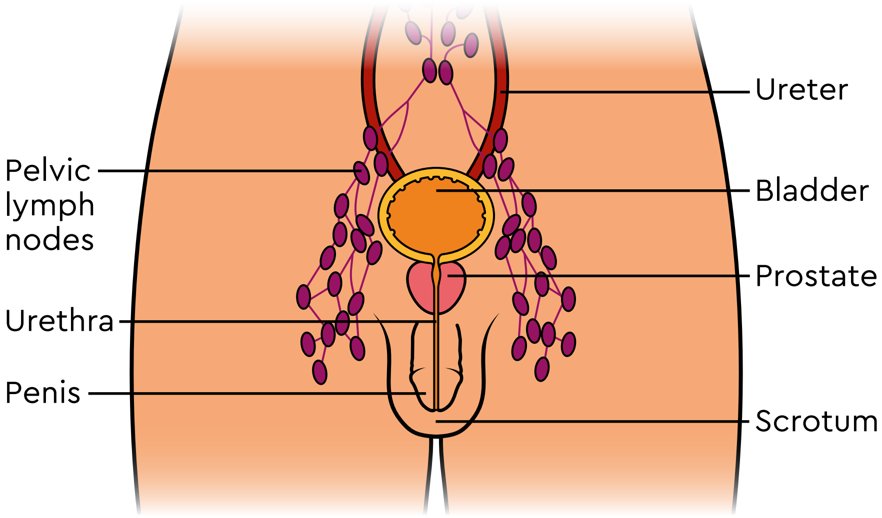
The lymphatic system

The lymphatic system is part of the body's immune system. This is the system that protects us from infection and disease. It is made up of fine tubes called lymphatic vessels. These tubes connect to groups of small lymph nodes throughout the body. Fluid drains from the tissues of the body into the lymphatic vessels. The fluid travels through the vessels and nodes, then into the bloodstream.

Lymph nodes are sometimes called lymph glands. They filter germs (bacteria), disease and waste products from the fluid as it passes through. When you have an infection, some lymph nodes may swell as they fight the infection.

If prostate cancer cells spread to the lymph nodes, they usually go to the nodes close to the prostate. You may have a scan to check if the cancer has spread to these nodes.

Pelvic lymph nodes



Locally advanced prostate cancer

Prostate cancer is the most common cancer in men in the UK. About 55,100 people are diagnosed with it each year. It is more common in people over the age of 65. It can happen at a younger age, but it is uncommon in people under the age of 50. There is a higher risk of getting prostate cancer at a younger age if you are Black or have a strong family history of prostate cancer.

Locally advanced prostate cancer is when the cancer has grown through the capsule surrounding the prostate. It may have started to spread into tissue or organs close by.

The results of your tests help tell your doctor the stage of the cancer and whether it is locally advanced. You can find out more about cancer staging on our website at macmillan.org.uk/prostate-cancer-staging

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

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

The LGBT Foundation can also give you confidential advice and support.

OUTpatients is a charity that supports LGBTQ+ people who have been diagnosed with cancer.

> "It's important to talk to other people because you then realise that you are not alone. You're not the only person going through this. There are lots of others out there feeling the same as you, and help is available."

Errol, diagnosed with prostate cancer

> **"When you are diagnosed, you only hear one thing: cancer. But my Macmillan nurse called me up that evening and told me all the things I'd forgotten or missed during the diagnosis. She said to call her whenever to talk through anything that I was worried about, which was amazing."**

Dougie, diagnosed with prostate cancer

Finding out you have locally advanced prostate cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with locally advanced prostate cancer.

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

Our booklet Tests for prostate cancer has information about symptoms, and the tests used to diagnose prostate cancer.

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer. Or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. They will be able to talk to you about what has happened and any worries you have.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Staging, grading and risk groups

Staging, grading and risk groups for prostate cancer 20

Staging of prostate cancer 21

Grading of prostate cancer 23

Risk groups for prostate cancer 25

Staging, grading and risk groups for prostate cancer

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

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

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

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

Staging of prostate cancer

Doctors often use the TNM staging system for prostate cancer.

TNM staging system

T describes the size of the tumour in the prostate gland.

N describes whether the cancer has spread to any lymph nodes. N0 means the cancer has not spread to the lymph nodes. N1 means there is cancer in 1 or more lymph nodes close by.

M describes whether the cancer has spread to another part of the body. This is called metastatic cancer. M0 means the cancer has not spread to another part of the body. Locally advanced prostate cancer is always M0.

T – Tumour

T1 – the tumour is within the prostate. It is too small to be felt during a digital rectal examination or seen on a scan. You can find out more about these tests in our booklet Having tests for prostate cancer.

Your surgeon may find cancer if you have surgery for another reason – for example, an enlarged prostate. T1 tumours are divided into:

- T1a – the cancer is found in 5% or less of the tissue removed
- T1b – the cancer is found in more than 5% of the tissue removed
- T1c – the cancer is found by a needle biopsy, which was done because of a raised PSA level.

T2 – the tumour is within the prostate. A doctor can feel it when they do a digital rectal examination. The tumour can also be seen on a scan.

T1 and T2 tumours are not likely to affect the lymph nodes or spread to other parts of the body. Doctors call this early or localised prostate cancer.

T3 tumours have spread outside the prostate capsule. T3 tumours are divided into:

- T3a – the tumour has spread through the capsule on one or both sides of the prostate
- T3b – the cancer has spread to the seminal vesicles.

T4 tumours have spread outside the prostate and may be growing into tissues or organs close by. If the cancer has not spread to another part of the body, such as the bones, it is called locally advanced prostate cancer.

When the cancer has spread to another area, it is called advanced or metastatic prostate cancer.

T3 and T4 cancers are called locally advanced prostate cancer.

You can contact your doctor or specialist nurse about your TNM staging. They can explain it to you.

Grading of prostate cancer

The grade of a cancer describes:

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

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

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

Gleason score

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

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

There may be more than 1 grade present in the biopsy. The doctor examines all the biopsy samples taken and identifies:

- the most common grade
- the highest other grade.

They add these together to give the Gleason score. For example, if the doctor finds the most common grade is 3 but the highest other grade seen in a sample is grade 4, then the Gleason score is 3 + 4 = 7.

Grade Group

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

Group 1 – Gleason score 6 (3+3)
The cancer cells look very similar to normal cells and are likely to grow very slowly, if at all.

Group 2 – Gleason score 7 (3+4)
Most of the cancer cells look like they will grow very slowly. Some may grow at a moderate rate.

Group 3 – Gleason score 7 (4+3)
Most of the cancer cells look like they will grow at a moderate rate. Some may grow very slowly.

Group 4 – Gleason score 8 (3+5, 4+4, 5+3)
The cancer cells look like they will grow at a moderately fast rate. Some may look like they will grow quickly.

Group 5 – Gleason scores 9 (4+5, 5+4) and 10 (5+5)
The cancer cells look like they will grow at a moderately fast rate or quickly.

Risk groups for prostate cancer

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

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

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

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

CPG1

This means:

- the cancer is T stage 1 or 2 **and**
- the Grade Group is 1 **and**
- the PSA is less than 10ng/ml.

The cancer is likely to grow very slowly and very unlikely to spread.

CPG2

This means:

- the cancer is T stage 1 or 2 **and**
- the Grade Group is 2 **or**
- the PSA is between 10 and 20 ng/ml.

The cancer is likely to grow slowly and is unlikely to spread.

CPG3

This means:

- the cancer is T stage 1 or 2 **and**
- the Grade Group is 2 **and**
- the PSA is between 10 and 20 ng/ml.

Or:

- the cancer is T stage 1 or 2 **and**
- the Grade Group is 3.

The cancer is more like to grow and spread outside the prostate.

CPG4

This means:

- the cancer is T stage 3 **or**
- the Grade Group is 4 **or**
- the PSA is more than 20ng/ml.

There is a higher risk of the cancer growing more quickly and spreading to another part of the body.

CPG5

You are in this group if you have 2 or more of the following:

- The cancer is T stage 3.
- The Grade Group is 4.
- The PSA is more than 20ng/ml.

You are also in this group if you have one of the following:

- The cancer is T stage 4.
- The Grade Group is 5.

There is a high risk of the cancer growing quickly and spreading to other parts of the body.

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

Preparing for treatment

Treatment overview 30

Treatment overview

There are different treatments for locally advanced prostate cancer. Treatments may be able to successfully treat and cure the cancer or keep it under control for many years.

Your cancer doctor and specialist nurse will help you understand what these treatments involve and how they may affect your life. Making treatment decisions can be difficult, but there is lots of information and support to help.

Your treatment will depend on:

- your general health
- your age
- the stage and grade of the cancer
- your preferences.

Your healthcare team will talk to you about what to consider when making treatment decisions. They will explain the benefits and disadvantages of each treatment. You and your healthcare team can then decide on the best treatment for you.

How you feel about treatments and your preferences are a personal choice. What is important to one person might not be to someone else.

You can also use the online decision aid called Predict Prostate. The infopool from Prostate Cancer Research has other tools to help with making decisions.

> **"There are different pathways for prostate cancer, with lots of different treatment options. My role is supporting patients from initial diagnosis to treatment and recovery. I am there to go through everything with them, answer any questions they have, and discuss treatment options. „**

Shona, Urology Clinical Nurse Specialist

Treatments

The main treatments include radiotherapy, hormonal therapy and watchful waiting. You may need a combination of treatments. Sometimes your cancer doctor may talk to you about having treatment as part of a clinical trial. We have more information about clinical trials on our website at macmillan.org.uk/clinical-trials

Radiotherapy

Radiotherapy uses high-energy x-rays to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. The aim of radiotherapy for locally advanced prostate cancer is to try to cure the cancer, or to control it for many years. Doctors call this radical radiotherapy.

External beam radiotherapy is the most common way of giving radiotherapy for locally advanced prostate cancer. Sometimes it is given with internal radiotherapy (brachytherapy).

External beam radiotherapy is given from outside the body (externally) using a radiotherapy machine. Internal radiotherapy is when a radioactive material is placed inside the body.

You usually have radiotherapy with hormonal therapy. Hormonal therapy can shrink the cancer, which helps make radiotherapy more effective. It also can reduce the risk of the cancer coming back somewhere else in the body in the future.

Some people may also be given another hormonal therapy called abiraterone for 2 years. Your cancer doctor can talk to you about whether this is an option for you. We have more information about abiraterone on our website at macmillan.org.uk/abiraterone

It is not common to have surgery if you have locally advanced prostate cancer. If you do, you may need radiotherapy afterwards.

Hormonal therapy

Prostate cancer needs testosterone to grow. Some hormonal therapies for prostate cancer reduce the amount of testosterone naturally produced in the body. Others stop testosterone from reaching the prostate cancer cells.

You may have hormonal therapy with radiotherapy to make treatment more effective. Your doctor may advise having hormonal therapy on its own if you:

- are older
- are on watchful waiting and the cancer starts to change
- do not want other treatments, or have health problems that would make it difficult.

Hormonal therapy can slow down or stop the cancer cells growing for many years. But it also has side effects.

Here is more information about hormonal therapy.

Watchful waiting (watch and wait)

In some situations, doctors may ask you to think about not having treatment straight away. Instead, they monitor the cancer. This is called watchful waiting.

The aim of watchful waiting is to control the symptoms of prostate cancer rather than cure it. You can have treatment if there are signs the cancer is growing, or if it is starting to cause symptoms.

If this happens, the doctor will usually recommend hormonal therapy. This will not cure the cancer, but it can often help control it for many years.

Surgery

Surgery to remove the prostate (radical prostatectomy) is not commonly done to treat locally advanced prostate cancer. Surgery may not be able to remove all the cancer cells that have spread outside the prostate. Sometimes, it may be done to try to prevent the cancer spreading. You may need to have radiotherapy afterwards. This may be months or years later.

Some people may have one of the following types of surgery if they are having difficulty passing urine (peeing):

- a transurethral resection of the prostate (TURP)
- a transurethral vaporisation of the prostate (TUVP).

A TURP or TUVP is not done to treat the cancer. But it can help you pass urine more easily again and improve symptoms.

You may have a TURP or TUVP before radiotherapy. This is because radiotherapy can make passing urine more difficult during and for a while after treatment.

Multidisciplinary team (MDT) meeting

A team of specialists meets to talk about the best treatment for you. This is called a multidisciplinary team (MDT).

The MDT looks at national treatment guidelines or the latest evidence for the type of cancer. If you have any treatment preferences, your doctor will tell them about this.

The MDT meeting will usually include the following professionals:

- A urologist or urological surgeon is a doctor who treats problems with and does surgery on the prostate, kidneys, bladder and male reproductive system.
- A clinical oncologist is a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- A medical oncologist is a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer.
- A clinical nurse specialist is a nurse who gives information about cancer, and support during treatment.
- A radiologist is a doctor who looks at scans and x-rays to diagnose problems.
- A pathologist is a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include:

- a pathway co-ordinator, who can provide information and guidance for other needs, such as financial support
- advanced nurse practitioners, who are specialist nurses for types of cancer and treatments – for example, surgical advanced nurse practitioners

- an advanced clinical practitioner, who is an expert healthcare professional, such as a nurse, who works with doctors to help assess people with cancer and manage their treatment and care.
- other healthcare professionals – for example, physiotherapists, occupational therapists or pharmacists, who are specialists in cancer and treatments.

Other people will be involved in your care. This includes medical and nursing staff on the wards or in different departments. If you have radiotherapy, you will meet a therapeutic radiographer. They are an expert in radiotherapy and are specially trained to give you treatment. They can also give you support, advice and information.

Talking about your treatment plan

After the MDT meeting, you usually meet with your cancer doctor and specialist nurse to talk about your treatment options. They will talk to you about your treatment plan. It can help to write down your questions before you meet with them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any decisions.

Your cancer doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

When you make treatment decisions, you may want to think about:

- the different side effects, and how they may affect your everyday life
- how much certain side effects are likely to bother you
- how you might cope with treatments if you have other health conditions
- whether the cancer is likely to cause you problems over your lifetime
- your feelings about treatment options
- what treatment options you have if the cancer comes back.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

You do not have to say why you do not want treatment. But explaining your decision may help your healthcare team understand your concerns and give you the best care.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website at macmillan.org.uk/second-opinion

Treating locally advanced prostate cancer

Radiotherapy 42

Hormonal therapy 64

Watchful waiting 74

Surgery 77

Clinical trials – research 98

Radiotherapy

Radiotherapy uses high-energy x-rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. The aim of radiotherapy for locally advanced prostate cancer is to try to cure the cancer, or control it for many years. Doctors call this radical radiotherapy. They try to make sure radiotherapy causes as little harm as possible to healthy tissue and nearby areas, such as the bladder and bowel.

Radiotherapy for prostate cancer can be given in 2 ways:

- External beam radiotherapy is given from outside the body (externally). It uses a radiotherapy machine called a linear accelerator (LINAC).
- Internal radiotherapy is when a radioactive material is placed inside the body. It is called brachytherapy

External beam radiotherapy is the most common way of giving radiotherapy for locally advanced prostate cancer. Sometimes it is given with brachytherapy.

You usually have radiotherapy with hormonal therapy. Hormonal therapy can shrink the cancer, which helps make radiotherapy more effective. Your cancer doctor may advise you to have hormonal therapy for 6 months before, during and after radiotherapy.

You may continue with hormonal therapy for up to 3 years. Some people may also be given another hormonal therapy called abiraterone for 2 years.

If you are having radiotherapy, you will meet with a clinical oncologist. A clinical oncologist is a cancer doctor who uses radiotherapy, chemotherapy and other cancer drugs to treat cancer.

You will also meet a therapeutic radiographer. Therapeutic radiographers are experts in radiotherapy and are specially trained to give you your treatment. They can also give you support, advice and information about your radiotherapy.

Smoking

If you smoke, it is important to try to stop. Stopping smoking can make radiotherapy work better. It also reduces the side effects of treatment.

Smoking also increases the risk of bone thinning. This is called osteoporosis.

Smoking is also a major risk factor for smoking-related cancers and heart disease. You can find out more about this in our booklet Heart health and cancer treatment.

It can be difficult to stop smoking, but you can get support. Your doctor or nurse can give you advice. There are also stop smoking services to help.

Here are details of organisations that can help you stop smoking.

What is external beam radiotherapy?

You have external beam radiotherapy as an outpatient in the radiotherapy department. Radiotherapy is given using a machine called a linear accelerator. This is often called a LINAC.

You usually have radiotherapy as a series of short, daily treatments (fractions). Each treatment lasts around 10 minutes. But you will be in the radiotherapy department for longer. The treatments are given from Monday to Friday, with a rest at the weekend. Radiotherapy is not painful, but you need to lie still while you have it.

Depending on the type of radiotherapy, treatment fractions are usually given over 1 to 4 weeks. Your cancer doctor or radiographer will explain your treatment plan.

The radiotherapy does not make you radioactive. It is safe for you to be with other people during external radiotherapy, including children.

Types of external beam radiotherapy

There are different ways of giving external beam radiotherapy. The type you have can depend on the risk group of the cancer and symptoms. These all target the prostate cancer very precisely. This aims to treat the cancer while protecting healthy tissue. This can help reduce side effects and late effects.

Intensity modulated radiotherapy (IMRT)

IMRT uses computers to calculate and deliver radiation directly to the cancer from different angles. It shapes the radiation beams to the size of the tumour. The strength (intensity) of the dose can be changed depending on the tissue. This means delivering a higher radiation dose to the cancer while giving lower doses to healthy tissue.

Volumetric modulated arc therapy (VMAT)

The radiation dose can be changed even more accurately during treatment. The machine rotates around you and delivers radiotherapy beams in continuous arcs (curves) precisely to the cancer. VMAT can be given in shorter treatment sessions.

Stereotactic ablative radiotherapy (SABR)

SABR allows large doses of radiotherapy to be given very precisely to small areas. The beams are directed from different angles that meet at the tumour. It involves giving larger doses of radiation to the prostate. This means you have treatment fractions over a few days, instead of weeks.

We have more information about SABR on our website at macmillan.org.uk/SABR

Planning external beam radiotherapy

Your cancer doctor plans your radiotherapy carefully to make sure it is as effective as possible while causing as few side effects as possible.

During the planning visit, you will have a CT scan. The scan is done to help your radiotherapy team plan the dose and area of your treatment. The hospital will send you information if you need to prepare for your scan.

We have more information about CT scans on our website at macmillan.org.uk/ct-scan

Before your scan, you may need to have a special diet or take medicine to empty your bowel. You may also need to drink water to fill your bladder. At some hospitals, you may be asked to go to the toilet so your bladder is empty. Doing these things helps get very clear CT pictures for planning your treatment.

You may have a small amount of liquid passed into your rectum to empty your bowel. This is called an enema. It helps you empty your bowel fully when you go to the toilet. You can usually do this yourself. If you need help, speak to your radiotherapy team.

During the scan, you need to lie still in the same position you will be in for your radiotherapy.

A therapeutic radiographer will give you your treatment. They may make some permanent marks (tattoos) the size of a pinpoint on your skin. These are used to make sure you are in the correct position for your treatment. They also show where the beams will be directed. This is only done with your permission. It may be a little uncomfortable. If you are worried about this, talk to the radiographer.

Sometimes you may have tiny, metallic grains passed into your prostate using an ultrasound probe. These are called fiducial markers. They help the radiographer see the position of the prostate before each session. This may help reduce side effects and possible damage to nearby areas, such as the bladder or bowel.

Image guided radiotherapy (IGRT)

The prostate can change position depending on the size of the bladder or bowel. With IGRT, the radiographers scan the prostate area before and sometimes during each session of radiotherapy. The scan pictures show the size and shape of the prostate cancer and the position of the bowel and bladder. The radiographers compare these pictures to the planning scan to check the position and the treatment area. They can then ensure the prostate is accurately targeted before each treatment. This makes the radiotherapy very precise.

Rectal spacers

A small amount of liquid gel, or an inflatable biodegradable balloon, is put into the space between the prostate and rectum before treatment. It moves the rectum away from the prostate and reduces the amount of radiation reaching the rectum. This can help reduce side effects to the rectum.

Rectal spacers are not available in all hospitals. They are not needed, or are not suitable, for everyone.

Your cancer doctor can tell you more about what is involved. You can ask them whether rectal spacers are available and whether they are suitable for you. They may be available through private healthcare.

Treatment sessions

The radiographer will explain what will happen. At the start of each treatment session, they make sure you are in the correct position on the couch and that you are comfortable.

When everything is ready, they leave the room and give you your treatment. This only takes a few minutes. You will be on your own during the treatment but can talk to the radiographers through an intercom or signal to them during the treatment. They can see and hear you from the next room.

During treatment, the radiotherapy machine may automatically stop and move into a new position. This is so the radiotherapy can be given from different directions.

> **"When you are lying on the linear accelerator having radiotherapy, you wonder, is this working? But 6 weeks later, I was given the all-clear. I couldn't believe it. I didn't expect to hear the words."**
>
> Dougie, diagnosed with prostate cancer

Side effects of external beam radiotherapy

Side effects usually build up slowly after you start treatment. They may continue to get worse for a couple of weeks after treatment. But after this, most side effects improve gradually over the next few weeks.

Your radiotherapy team will talk to you about this. They will explain what to expect and give you advice on what you can do to manage side effects.

Always tell them about your side effects rather than trying to treat them yourself. There are usually things they can do to help. We list the common side effects here, but you may not get all of these. We have more detailed information about pelvic radiotherapy in our booklet Understanding pelvic radiotherapy.

Bladder side effects during treatment

Radiotherapy can also cause inflammation of the bladder. This is called radiation cystitis. You may:

- feel you want to pass urine (pee) more often (frequency)
- have a burning feeling when you pee
- be unable to wait to empty your bladder (urgency)
- have difficulty in starting to pee.

Your cancer doctor or radiographer can prescribe medicines to help. Drinking 2 to 3 litres (3½ to 5½ pints) of fluids a day can help. Avoid drinks containing caffeine and alcohol. These side effects usually disappear slowly a few weeks after treatment has finished.

Some people may have difficulty passing urine, but this is rare. If you are having problems, you may need to have a tube put into the bladder to drain urine. This is called a urinary catheter.

Side effects can be worse if you already had bladder problems before starting radiotherapy. If you already had bladder problems before treatment, you may find them start to improve after radiotherapy finishes. We have more information in our booklet Managing the bladder late effects of pelvic radiotherapy.

Bowel side effects during treatment

Radiotherapy to the prostate can irritate the lower bowel (rectum). You may get diarrhoea, wind and cramping pains in your tummy (abdomen). You may feel your bowel is not completely empty after going to the toilet. You may notice blood or mucus when you go to the toilet. It is important to tell your radiotherapy team about bowel side effects.

If you have diarrhoea, drink at least 2 to 3 litres (3½ to 5½ pints) of fluids a day. Avoid caffeine and alcohol. During treatment, your radiographer may advise you to make some changes to your diet, such as eating less fibre. These side effects usually improve by 6 weeks after finishing treatment.

Your cancer doctor, specialist nurse or pharmacist may give you anti-diarrhoea drugs to take at home. It is important to follow their advice about taking the drugs.

Symptoms can often be managed with medication and changes to your diet. If problems do not improve, you can ask to be referred to a late effects specialist or a bowel specialist – this may be a gastroenterologist or bowel surgeon. We have more information about bowel problems after pelvic radiotherapy in our booklet Managing the bowel late effects of pelvic radiotherapy.

Tiredness

Radiotherapy often makes people feel tired. Hormonal therapy can add to the tiredness. Tiredness (fatigue) may get worse as treatment goes on. There are things you can do to help:

- Get plenty of rest, but keep your daily routine if you feel able to.
- Do some regular exercise, such as going for a walk.
- Eat a healthy diet and drink plenty of fluids.
- Ask for help with everyday tasks, if you have friends or family members who can support you.

After treatment finishes, tiredness should improve. If it does not get better after a few weeks, tell your cancer doctor or specialist nurse.

We have more information about coping with fatigue (tiredness) in our booklet and audiobook Coping with fatigue (tiredness).

Effects on the skin

Less commonly, the skin in the treated area may change colour. If you have white skin, it may become red. If you have black or brown skin, it may look darker.

The skin may also become dry or flaky, and feel itchy or tight. Sometimes the skin around the anus and scrotum becomes moist and sore. Your radiographer will give you advice. Your cancer doctor or radiographer can prescribe a cream or dressings and painkillers if you need them.

Your pubic hair may fall out. It usually starts to grow back a few weeks after you have finished treatment. It may be thinner than before.

Erection problems

Radiotherapy for prostate cancer can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). ED may not happen straight away, but it can develop slowly over 2 to 5 years. About 30 to 45 out of 100 people (30% to 45%) who do not have any problems before radiotherapy develop ED after treatment.

You can find out more about ED on our website at macmillan.org.uk/male-pelvic-side-effects

You may have a higher risk of ED if:

- you are older
- you already had ED before treatment
- you have other medical problems that also cause ED, such as diabetes or heart disease
- you are taking hormonal therapy, which also causes ED and affects your desire to have sex (libido).

Ask your radiotherapy team about your risk of ED. If you develop ED, there are different treatments that can help.

After radiotherapy and brachytherapy, orgasms might feel different and you might ejaculate little or no semen. Hormonal therapy can also make your penis appear shorter in length. Your cancer team can talk to you about ways of preventing or helping this.

Infertility

Radiotherapy to the prostate may cause permanent infertility. If you find this difficult to cope with or are worried, talk to your cancer doctor. You may be able to store sperm before treatment starts. We have more information in our booklet Cancer and fertility.

Late effects of external beam radiotherapy

Side effects that do not improve or happen months to years after radiotherapy are called long term or late effects. Improved ways of giving radiotherapy are reducing the risk of late effects, particularly on the bowel. Your radiotherapy team will explain these to you. You can find out more about your radiotherapy team on our website at macmillan.org.uk/radiotherapy-team

Late bladder effects

Bladder side effects you get with treatment (frequency and urgency) may not completely go away, or they may develop later. Sometimes radiotherapy can affect how well your bladder can hold urine.

The bladder lining may bleed easily, causing blood in your urine. This is called haematuria. You may get leakage of small amounts of urine (urinary incontinence). But this is rare. We have more information about how bladder problems may be treated in our booklet Managing the bladder late effects of pelvic radiotherapy and on our website at macmillan.org.uk/bladder-late-effects

Late bowel effects

With newer radiotherapy methods, late effects to the bowel are less common. Late effects may be similar to the immediate side effects. You may feel you need to rush urgently to go to the toilet. Or, rarely, you might have some leakage or soiling (bowel incontinence). Sometimes blood vessels in the bowel lining become more fragile and bleed. If you notice any bleeding, always tell your doctor so they can check it.

Symptoms can often be managed with medication and changes to your diet. If problems do not improve, you can ask to be referred to a late effects specialist or a bowel specialist. This may be a gastroenterologist or bowel surgeon. We have more information about bowel problems after pelvic radiotherapy in our booklet Managing the bowel late effects of pelvic radiotherapy and on our website at macmillan.org.uk/bowel-problems-pelvic-radiotherapy

Brachytherapy

Brachytherapy (internal radiotherapy) gives high doses of radiation directly to the prostate. Areas close by get a much lower dose – for example, the bladder and bowel. Doctors may use high dose rate (HDR) brachytherapy with external radiotherapy to treat locally advanced prostate cancer. They sometimes call it a boost dose. You usually have it 1 to 2 weeks before you start external radiotherapy or when you finish external radiotherapy.

HDR brachytherapy involves placing thin tubes into the prostate. They are attached to a machine that sends a radioactive source into the tubes for a set time.

There may be some differences in how each hospital gives brachytherapy. Your cancer doctor, radiologist or specialist nurse will explain what will happen.

You usually have antibiotics before brachytherapy and for a few days after to help prevent infection. You may also be given tablets to help you pass urine (pee) more easily after treatment. Your cancer doctor or radiographer can tell you how long to take these for.

HDR brachytherapy

To have HDR brachytherapy, you will have a general anaesthetic or a spinal anaesthetic – this is an injection into the spine. If you have a spinal anaesthetic, you will be awake but will not feel any pain. You will be given a sedative so that you feel sleepy and more relaxed. You may need to stay in hospital overnight.

Having the tubes put in

Your doctor passes an ultrasound probe into the anus into the rectum to take pictures of the prostate. This helps your cancer doctor plan the number of tubes needed and where they should be placed. They may also use a CT scan to help position the tubes.

Your cancer doctor passes the tubes into your prostate through the skin between the scrotum and back passage. This is called the perineum. They may also put a tube into the bladder to drain urine. This is called a catheter. This prevents swelling of the prostate from stopping you passing urine. They remove the catheter before you go home.

When the tubes are in, you have a CT or MRI scan. This helps your cancer doctor plan exactly how much radiation to give the prostate.

We have more information on our website about CT scans at macmillan.org.uk/ct-scan and MRI scans at macmillan.org.uk/mri-scan

Having HDR

You will be taken into a treatment room that has the HDR machine. The tubes are attached to the machine. The machine sends the radioactive source into the tubes going into the prostate. A computer monitors how long the radioactive source stays in place. The treatment takes about 1 hour.

The tubes can be uncomfortable, and you must stay lying down while they are in place. After HDR brachytherapy is finished, the radioactive material is returned to the machine and the tubes are removed.

After treatment

After treatment, you have no radioactive material inside you, so there is no risk in being around other people.

Your radiotherapy team will explain what to expect after treatment. Before you go home, they will give you antibiotics and tablets to help you to pass urine more easily. Take them exactly as explained.

You need to avoid doing heavy lifting or energetic physical activity for 2 to 3 days. The area can feel bruised and swollen for a few days. Your GP, cancer doctor or pharmacist can advise you about pain killers.

Side effects of brachytherapy

Brachytherapy causes similar side effects to external beam radiotherapy. Having brachytherapy with external beam radiotherapy may make some side effects more severe. Some side effects may take several weeks to develop and may last for longer.

Erection problems

Brachytherapy for prostate cancer can cause problems getting and keeping an erection. This is called erectile dysfunction (ED).

You may have ED immediately after treatment due to swelling and bleeding. But this can improve as these problems settle down. Sometime ED develops gradually over months or years.

The risk of permanent ED after brachytherapy varies. If you had ED before brachytherapy, it is more likely you will have it afterwards. Having external radiotherapy and hormone therapy will also increase the risk of ED.

Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help.

After brachytherapy, orgasms might feel different and you might ejaculate little or no semen.

We have more information about sexual difficulties.

We have more information about wellbeing and recovery.

Bowel problems

Brachytherapy may cause some bowel problems for a few weeks after treatment. These are similar to the side effects caused by external radiotherapy. Sometimes they last for months.

Brachytherapy on its own is less likely than external beam radiotherapy to affect the bowel and cause late bowel effects. Late bowel effects are side effects that do not go away after cancer treatment or do not happen until months or years later. If bowel problems do not improve or develop later on, contact your doctor straight away. Always tell them if you notice any bleeding. We have more information about this on our website at macmillan.org.uk/bowel-problems-pelvic-radiotherapy

Effects on the bladder

These can be more of a problem after brachytherapy. If you already have difficulties passing urine (peeing), you will not usually have brachytherapy, as it may make bladder problems worse.

You may notice some blood in your urine and semen for a few weeks after treatment. If bleeding gets worse or you notice large blood clots, contact the hospital straight away. Drinking plenty of water helps flush your bladder and prevent blood clots.

You may also:

- have discomfort or pain passing urine
- need to pass urine urgently and more often.

Drinking plenty of water and avoiding caffeine and alcohol will help improve these symptoms.

With HDR brachytherapy, these symptoms should improve after a few weeks.

Not being able to pass urine

Brachytherapy may cause swelling of the prostate. This may make it difficult to pass urine. If this happens, you may need to have a catheter put in your bladder until the swelling goes down. This usually takes 2 to 4 weeks. Sometimes a catheter needs to be in for a longer time until you can have surgery to remove part of the prostate (TURP).

Sometimes radiotherapy can narrow the urethra. This is called a urethral stricture. This causes difficulty with passing urine. This may happen weeks, months or even years after treatment finishes. There are different treatment options for urethral stricture:

- Sometimes a thin, plastic tube can be passed through the urethra to widen (dilate) it.
- Some people may have a small scope passed into the urethra. Then either a tiny knife or laser is passed through the scope to cut along the stricture to widen the urethra.
- If none of these treatments work, you may need surgery.

Your treatment will depend on factors such as the position and length of the stricture, as well as your age and general health.

Infertility

Having brachytherapy on its own can still cause infertility, but the risk may be lower than with external beam radiotherapy. If you find this difficult to cope with or are worried about your fertility, talk to your cancer doctor. You may be able to store sperm before treatment starts.

We have more information about cancer and fertility in our booklet Cancer and fertility.

Hormonal therapy

Prostate cancer needs the hormone testosterone to grow. Testosterone is mainly made by the testicles.

Hormonal therapies reduce the amount of testosterone in the body, or stop testosterone reaching the prostate cancer cells.

Testosterone is important for:

- sex drive (libido)
- getting an erection
- facial and body hair
- muscle development and bone strength
- heart health.

Hormonal therapy with radiotherapy

Doctors usually advise having hormonal therapy with radiotherapy to treat locally advanced prostate cancer.

You usually have radiotherapy with hormonal therapy. Hormonal therapy can shrink the cancer, which helps make radiotherapy more effective. Your cancer doctor may advise you to have hormonal therapy for 3 to 6 months in the time before, during and after radiotherapy. Or you may continue with hormonal therapy over a longer period, for up to 3 years. Your cancer doctor can tell you how long is suitable for you.

> **"My treatment was radiotherapy with hormonal therapy. I started the hormonal therapy first. I took tablets for a month and had an injection. I then had a brachytherapy procedure followed by radiotherapy. I gained a bit of weight from the hormonal therapy."**
>
> David, diagnosed with prostate cancer

Abiraterone

In addition to the longer hormonal therapy, some people may also be given another hormonal therapy called abiraterone for 2 years. Your cancer doctor can talk to you about whether this is an option for you.

Until recently, abiraterone has only been used to treat prostate cancer that has spread to other parts of the body. This is called advanced or metastatic prostate cancer.

Clinical trials have now shown that abiraterone may be helpful in treating high risk prostate cancer that has not yet spread to other parts of the body (non-metastatic cancer).

Abiraterone tablets are usually taken once a day. They should not be taken with food as it can affect how abiraterone works and increase side effects.

Abiraterone is taken with a daily steroid tablet. The steroids help reduce some of the side effects of abiraterone. We have more information about abiraterone on our website at macmillan.org.uk/abiraterone

Hormonal therapy on its own

If your doctors are using the watchful waiting approach and the cancer starts to grow, you may have hormonal therapy on its own.

Depending on your general health and preferences, you may decide to have hormonal therapy on its own instead of radiotherapy. Unlike radiotherapy, it does not aim to get rid of all the cancer cells. But it may be suitable if you are not well enough to have radiotherapy, or do not want to have it.

Hormonal therapy can slow down or stop the cancer cells growing for many years. It can improve the symptoms caused by the cancer. Not having radiotherapy means you avoid its side effects, such as bladder and bowel effects. But hormonal therapy can also cause side effects. It is important to talk to your cancer doctor or specialist nurse before you decide.

Intermittent hormonal therapy

Intermittent hormonal therapy may sometimes be an option. This is when you stop taking hormonal therapy tablets for a time, then start taking them again after a while. This is to give you a break from the side effects of hormonal therapy. Intermittent hormonal therapy is not suitable for everyone and should only be done following your cancer doctor's advice. Your cancer doctor can explain more about this. They usually measure your PSA level every 3 months. If your PSA goes up to a certain level or you get symptoms, your doctor may advise you to start having hormonal therapy again.

Types of hormonal therapy

There are different types of hormonal therapy. Your cancer doctor, specialist nurse or pharmacist will explain the treatment that is most suitable for you.

LHRH agonists

The pituitary gland in the brain makes a hormone called luteinising hormone (LH). This hormone tells the testicles to make testosterone.

LH-releasing hormone (LHRH) agonists interfere with this action and stop the testicles making testosterone. You have them as an implant injection or an injection under the skin.

The commonly used LHRH agonists are:

- goserelin (Zoladex®, Zoladex LA®)
- leuprorelin
- triptorelin (Decapeptyl®, Gonapeptyl®).

You can find out more about these on our website at macmillan.org.uk/treatments-and-drugs

Your practice nurse at your GP surgery can give you these drugs. If you are not able to visit the GP surgery, a district nurse may give you the injections at home. Or they may be given by a nurse at the hospital.

You have goserelin as an injection of a small pellet (implant) under the skin of your tummy (abdomen). The drug is released slowly as the pellet dissolves. You have it every 4 weeks, or as a longer-acting injection every 12 weeks.

Leuprorelin and triptorelin are given as an injection under the skin (subcutaneously) or into a muscle (intramuscularly). You have these monthly, or every 3 or 6 months. Your cancer doctor, specialist nurse or pharmacist will talk to you about your treatment plan.

The first time you have one of these drugs, it can cause a temporary increase in testosterone. This can make any symptoms worse for a short time. This is sometimes called tumour flare. To prevent this, your doctor usually asks you to take an anti-androgen drug, such as bicalutamide. You take it for a short time before and after starting the LHRH agonist.

GnRH antagonists

Gonadotropin-releasing hormone (GnRH) antagonists block messages from the brain to the testicles that tell them to make testosterone. They do not cause tumour flare, so you do not need to take an anti-androgen with a GnRH antagonist.

Some people may have a GnRH antagonist called relugolix (Orgovyx®). Relugolix is taken as tablets. This drug may be used if you have other health conditions. We have more information about relugolix on our website at macmillan.org.uk/relugolix

Anti-androgen drugs

An anti-androgen drug stops testosterone from reaching the cancer cells. This is usually a drug called bicalutamide. You take bicalutamide as tablets. You may have it with radiotherapy, instead of having an LHRH agonist with radiotherapy. Or you may have bicalutamide before and after the first injection of an LHRH agonist. This is to prevent any symptoms getting temporarily worse – for example, tumour flare.

Side effects of hormonal therapy

Reducing the level of testosterone can cause different side effects. There are different ways hormonal side effects can be managed or treated. Your cancer doctor, specialist nurse or pharmacist will explain this to you. Some side effects are only likely to affect you when you have hormonal therapy for more than 6 months.

Different hormonal therapies have different side effects. It is important to discuss these with your cancer doctor, specialist nurse or pharmacist before treatment, so you know what to expect.

Common side effects

Common side effects of hormonal therapy include the following.

Erection difficulties and reduced sex drive

Hormonal therapy may make it difficult for you to get or keep an erection. This is called erectile dysfunction (ED). This will usually improve slowly over a few months after you stop hormonal treatment, depending on how long you take it for. Hormonal therapy may also lower your desire to have sex (libido).

Hormonal therapy can also cause some changes to the penis – for example, it may appear shorter. Your cancer team can talk to you about ways of preventing or helping this.

If you have ED, there are drugs and treatments that may help. Even with a low sex drive, some ED treatments may work for you.

There is more information about hormonal therapy and sexual difficulties.

Hot flushes and sweats

Hormonal therapy can cause hot flushes. These may reduce as your body adjusts to hormonal treatment. In most cases, they gradually improve after treatment finishes. Talk to your cancer doctor or specialist nurse if you are having problems. They can give you advice and may be able to prescribe medicines to help.

Tiredness and difficulty sleeping

Feeling tired is a very common side effect of hormonal therapy. We have more information about tiredness in our booklet Coping with fatigue (tiredness).

Regular physical activity, such as walking, can help reduce tiredness. Physical activity can also help reduce other side effects from hormonal therapy. Try to keep to your regular routine if you can. We have more information about physical activity in our booklet Physical activity and cancer.

Hot flushes may make sleeping difficult, so managing them may help you to sleep better.

Mood changes

During hormonal therapy, you may have mood swings, or feel low or depressed. Talking to family and friends about how you feel might help. If mood changes last for more than a few weeks, tell your GP, cancer doctor or specialist nurse. They can talk to you about different ways to manage low mood or depression.

Memory and concentration problems

Problems with memory and concentration may be caused by the hormonal therapy, or because of tiredness or feeling anxious.

Other side effects

If you have hormonal therapy for 6 months or more, you may have other side effects. The benefits of hormonal therapy generally outweigh the possible risks. Your cancer doctor, specialist nurse or pharmacist will talk to you about this.

Other possible side effects include the following.

Weight gain and loss of muscle strength

You may gain weight (especially around the middle) and lose muscle strength. Regular physical activity and a healthy, balanced diet can help manage this.

You might find it helpful to read our booklets:

- Physical activity and cancer
- Healthy eating and cancer.

Breast swelling or tenderness

Breast swelling or tenderness is more common if you have flutamide or bicalutamide over a longer period. You may be given low dose radiotherapy to your chest before treatment to prevent breast swelling. If you are taking bicalutamide, another option is to take a hormonal drug called tamoxifen to reduce breast swelling.

We have more information about bicalutamide on our website at macmillan.org.uk/treatments-and-drugs

Bone thinning (osteoporosis)

The risk of osteoporosis is increased with long term hormonal therapy. You may have a scan to check your bones before you start treatment. Regular weight-bearing exercises such as walking, dancing, hiking, or gentle weightlifting can help keep your bones healthy. Your cancer doctor or specialist nurse may give you advice on diet and exercise.

Your cancer doctor, specialist nurse or pharmacist may advise you to take calcium and vitamin D tablets. Depending on your bone health, your cancer doctor may talk to you about bone-strengthening drugs called bisphosphonates.

We have more information about bone thinning in our booklet Bone health and cancer treatment.

Increased risk of heart disease and diabetes

Not smoking, being physically active, eating healthily and keeping to a healthy weight can help reduce the risk of heart disease and diabetes.

You might find it helpful to read our booklets:

- Heart health and cancer treatment
- Diabetes and cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Watchful waiting

In some situations, doctors may ask you to think about not having treatment straight away. Instead, they monitor the cancer. Doctors call this watchful waiting (watch and wait).

Your doctor might talk to you about watchful waiting if:

- you are older and do not have symptoms
- you have another medical condition that makes having treatment difficult
- you decide you want to avoid or delay treatment and its side effects.

The aim of watchful waiting is to control the symptoms of prostate cancer rather than cure it. You do not have regular scans or start treatment unless the cancer is changing, or you get symptoms. This means you avoid treatment and its side effects for as long as possible.

You will meet with your doctor regularly. This is usually your GP. Sometimes it may be your urologist, cancer doctor or specialist nurse. They will ask if you have any new symptoms – for example, bone pain or difficulty passing urine (peeing). If you do have symptoms, you may have regular blood tests to check your PSA levels.

Many people on watchful waiting will never need any treatment for their prostate cancer. If you develop any symptoms, or your PSA level rises, your GP will refer you back to the specialist at the hospital. They will usually recommend hormonal therapy. This will not cure the cancer, but it can often help control it for many years.

Surgery

Surgery to remove the prostate to treat prostate cancer is called a radical prostatectomy. There are different types of radical prostatectomy. The surgery is done by a urologist or urology surgeon who specialises in treating prostate cancer and performs this type of surgery often. Not all urologists do surgery for prostate cancer.

The aim of the surgery is to remove the cancer by removing the prostate. A radical prostatectomy is not always suitable when the cancer is locally advanced. It may not be possible to remove all the cancer cells that have spread outside the prostate. The urologist and specialist nurse can talk to you about whether a radical prostatectomy would be suitable for you, or whether other treatment such as radiotherapy may be best for you. They may refer you to an oncologist (cancer doctor) to talk about other treatment options.

There is also surgery that can help with symptoms. A transurethral resection of the prostate (TURP) does not treat the cancer, but it can help urinary symptoms, such as difficulty passing urine (peeing). It is sometimes done before other treatments such as radiotherapy. This is because radiotherapy can make urinary symptoms worse during and for a while after treatment.

Before surgery, the urologist and specialist nurse will explain what will happen and tell you about any possible side effects. You will be given written information to take away. It is important you have all the information you need to decide about having surgery. We have more information on our website about:

- talking to your healthcare team – visit macmillan.org.uk/talk-healthcare-team
- support to understand information – visit macmillan.org.uk/understanding-information

Types of surgery

There are different ways of doing a radical prostatectomy. Your surgeon will explain the type of surgery you will have. It is usually laparoscopic (keyhole) surgery. This is often robotic-assisted laparoscopic surgery. Occasionally, it may be open surgery.

During a radical prostatectomy, the surgeon frees the prostate gland from the bladder and urethra so that it can be removed. They rejoin the urethra to the bladder using dissolvable stitches. They also remove the seminal vesicle, the part of the body that helps make semen. They may also remove the lymph nodes close to the prostate and check them for cancer cells. This depends on your risk of having cancer in the lymph nodes.

A radical prostatectomy is usually done under a general anaesthetic, which means you are not awake when you have the procedure. But it can also be done under a spinal anaesthetic. If you have a spinal anaesthetic, you will be given a sedative to help you relax and feel sleepy.

You will meet with an anaesthetist to talk about which anaesthetic you will have, and pain control after the surgery.

We have more information about the healthcare professionals you might meet when having surgery, and about types of anaesthetic, on our website at macmillan.org.uk/surgery-MDT

Laparoscopic (keyhole) radical prostatectomy

In this type of surgery, the surgeon does not need to make a large cut. Instead, they remove the prostate using 5 or 6 small cuts in the tummy area (abdomen). Each cut is about 1cm long.

The surgeon puts a small tube with a light and camera on the end through one of the cuts. This is called a laparoscope. The camera shows an image of the prostate on a screen. The surgeon uses small, specially designed equipment to cut away the prostate from the bladder and urethra. They remove the prostate through one of the small cuts.

Robotic-assisted laparoscopic radical prostatectomy

Robotic-assisted surgery is when a laparoscopic radical prostatectomy is assisted by a machine. Instead of the surgeon holding the laparoscope and the equipment, they are attached to robotic arms. The surgeon controls the robotic arms, which they move very precisely. The aim of robotic-assisted surgery is to help prevent damage to the nerves in the area. These are the nerves that control your bladder and erections.

Surgeons need special training to do robotic-assisted surgery, and not all hospitals have a robot. Your urologist can tell you whether this surgery is suitable for you, and whether you need to go to another hospital.

Open radical prostatectomy

During open surgery, the surgeon makes one larger cut in your abdomen. It goes downwards from your belly button. They remove the prostate and seminal vesicles through this cut, and lymph nodes if needed. Sometimes a cut can be made in the area between the scrotum and anus instead. This is called the perineum.

Before surgery

Before a radical prostatectomy, the surgeon and specialist nurse will explain the possible risks and side effects.

Before surgery, your healthcare team may advise you on what you can do to be fitter for surgery, such as stopping smoking, being more physically active or eating healthily. This is called prehabilitation.

You can find out more about prehabilitation on our website at macmillan.org.uk/prehab

Some hospitals might have a prehabilitation service. But if there is not, your prehabilitation may involve specific help and support to prepare for surgery from your surgeon, specialist nurse and other professionals in the MDT.

Your surgeon and specialist nurse may also talk about things you can do to reduce the time you spend in hospital and help you to recover as quickly as possible. This is called enhanced recovery.

Before your surgery, you may also have a pre-operative assessment. This may involve having some tests to check your general health and fitness. You can also learn more about how to prepare for your surgery at this appointment. You may be invited to a group education session about having a radical prostatectomy.

You will be encouraged to start pelvic floor exercises to strengthen the pelvic floor muscles. You can do these at home. This can help reduce urinary leakage (incontinence) after the surgery.

We have more information about pelvic floor exercises on our website at macmillan.org.uk/pelvic-floor-exercises

If you think you might need help at home after surgery, tell your nurse when you go into hospital. They can talk to you about the support that is available. We have more information about:

- preparing for surgery – visit macmillan.org.uk/preparing-surgery
- going home from hospital – visit macmillan.org.uk/going-home-from-hospital

We also have more information for carers in our information about looking after someone with cancer in our booklet Looking after someone with cancer.

Going into hospital

You usually go into hospital on the day of your surgery, or the day before. When you arrive, the nurses on the ward will explain what to expect and give you some information. They will give you an identity bracelet with your details on it. You might find you meet different healthcare professionals and you may be asked the same questions each time. This is just to check everything is correct at each stage of your care.

Ask questions if you are unsure about anything. The nurses would prefer you to ask than be worried.

If you are going into hospital on the day of your surgery, you may be asked not to eat or drink anything for a few hours. This is sometimes called nil-by-mouth.

If you have diabetes, make sure the doctors and nurses know about this. You can find out more about diabetes and cancer in our booklet Diabetes and cancer treatment.

Follow any advice you are given at the pre-operative assessment about taking your usual medicines. You can usually still take these with a sip of water, but you should check with the doctor and nurses.

Your nurse will give you compression stockings to put on before surgery. These are called TED stockings. You will also have to wear these for a period of time afterwards. Compression stockings reduce the risk of getting a blood clot in your legs. This is called deep vein thrombosis or DVT.

Compression socks and stockings need to be the right size with no folds or wrinkles to work effectively. Your nurse will measure you and then check they fit and are on properly.

After a radical prostatectomy

If you are having a general anaesthetic, your surgeon, anaesthetist or nurses will explain what to expect when you wake up after surgery. You are usually moved to the recovery room in the operating department to be monitored until you are awake. You are then moved back to the ward a short time later.

You might feel drowsy at first if you had a general anaesthetic. You may notice your face is a bit puffy. This is because your head is tipped downwards during the surgery.

Immediately after surgery, the nurses can help you with washing and going to the toilet. But they will encourage you to be up and moving around as soon as possible. They can help you move safely with your catheter. You may feel anxious about this, but moving around prevents complications and helps your recovery.

You will usually have a drip into a vein in your arm. This is called an intravenous infusion. It will stay in for a few hours after your operation, until you are eating and drinking again.

We have more information about what to expect after surgery on our website at macmillan.org.uk/after-surgery

Wound

After open surgery, you will either have a wound on your tummy area (abdomen) or perineum. This is the area between the scrotum and the anus. After laparoscopic surgery, you will have 5 or 6 small wounds in the abdomen. If you had open surgery, you may also have a small tube going into the wound. This is called a drain. It helps to remove any fluid that is collecting there. It is usually removed after a few days.

Before you go home, the nurses on the ward will advise you on how to take care of your wound. They will advise you on what to look out for and who to contact if you have any concerns.

Pain

After surgery, you will have some bruising or swelling around the cuts and also in your scrotum.

You may have some pain or discomfort after surgery. Painkillers will help with this. In hospital, you may have pain medicines through a drip in your vein, or by injection. This will then be replaced with painkiller tablets. Tell the nurses on the ward if you are still in pain. They will give you tablets to take home with you and explain how to take them.

You might have some discomfort for a couple of weeks, particularly when you walk. Taking regular painkillers should help. Talk to your GP, specialist nurse or pharmacist if you are still getting pain.

Urinary catheter

During surgery, you will have a tube put in to drain urine from your bladder. This is called a catheter. The catheter keeps your bladder empty while the urethra heals. Try to drink plenty of fluids to help keep the catheter draining well.

The nurses on the ward will show you how to look after your catheter before you go home. They will give you spare bags to take home. If you need more support, they can arrange for a district or community nurse to visit you at home.

The nurses will give you details of who to contact if you have any problems or concerns about your catheter. The catheter is usually removed 1 to 2 weeks after surgery. The nurses may give you a clinic appointment date to have this done. Ask the nurses on the ward before you go, or call the number you have been given if you are not sure about anything to do with your catheter.

You will leak urine for a while after the catheter is removed. This is expected and should slowly improve. You will need to wear a pad in your underwear for a while, but the need for pads should lessen. Your surgeon and specialist nurse can talk to you about what to expect.

> **"I never really had any pain after my operation, once the catheter had been removed. Urinary incontinence was not bad either. It improved very quickly."**
>
> Simon, diagnosed with prostate cancer

Preventing blood clots

After your surgery, the nurses will encourage you to be up and moving around. This can help prevent complications such as blood clots in the veins in the legs. You will continue to wear your compression stockings for a while. Your nurse can explain how long to wear them for. They can talk to you about how to wash and care for them. They may give you a spare pair to take home.

The nurse may give you an injection under the skin to help prevent blood clots. When you go home, you are usually given more of the small injections. You usually have these for 28 days. The nurses can show you or your carer how to give them. They may organise for a district or community nurse to give them instead.

Going home

If you had laparoscopic or robotic surgery, you usually go home after 1 to 2 days. After open surgery, it is usually between 3 and 7 days. Before you leave hospital, your hospital doctor will send a letter called a discharge summary to your GP. The letter is usually sent electronically so that your GP gets it within 24 hours of your discharge. You are usually given a copy to take home with you. It will explain your diagnosis, what type of surgery you had, any medication you are taking and about your follow-up care.

If you need a district or community nurse, the ward nurses will organise this before you go home. You should also be given 24-hour telephone numbers for your hospital team in case you need to contact them.

You can usually get back to normal activities 4 to 12 weeks after surgery, depending on the operation you had. If you had robotic-assisted surgery, you usually recover faster.

It is important to remember that even if you have small wounds, you have still had major surgery. You will feel tired, so try to get plenty of rest and eat well. Do some light exercise, such as walking, to build up your energy. You can slowly increase the amount you do.

Your surgeon, specialist nurse or nurses on the ward can give you advice on when you can start doing things such as driving or returning to work. They can also give you advice on when you can have sex again. We have more information about sex and prostate cancer.

Follow-up after surgery

You will have a clinic appointment to meet with the surgeon. They will check that your wound is healing properly and tell you about:

- results from the tissue removed during surgery (pathology)
- the stage of the cancer
- any further cancer treatment you may need
- your recovery after surgery.

Side effects of a radical prostatectomy

There are side effects after a radical prostatectomy. Some side effects improve over time, but some are permanent.

Erection problems

Surgery to the prostate can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). This is caused by damage to the nerves and blood vessels close to the prostate. These are the nerves and blood supply that help you get an erection.

Surgeons can operate in a way that tries to protect these nerves or blood vessels. This is called a nerve-sparing technique. It is only possible if the cancer has not spread to the edges of the prostate. During surgery, if the surgeon thinks there is cancer in the nerves or surrounding area, they remove some or all the nerves.

Whether you will have problems getting an erection after a nerve-sparing operation depends on different factors. For example, it may depend on your age and whether:

- you had erection problems before surgery
- you have any other medical conditions, such as diabetes
- you are taking medicines for high blood pressure
- you have had surgery called a transurethral resection of the prostate (TURP)
- the surgeon was able to spare some or all of the nerves.

You can ask your surgeon about your risk of ED. Your ability to have an erection may slowly return after surgery. But this may take 1 or 2 years. It is less likely to return if you have further treatment after surgery, such as hormonal therapy or radiotherapy.

You may be offered penile rehabilitation using different ED treatments soon after surgery. This is called an ED recovery package. We have more information about treatments to help ED on our website at macmillan.org.uk/erection-problems

Ejaculation

When you have your prostate removed, you can still have an orgasm even without an erection, but there will be no ejaculation. This is called a dry ejaculation or dry orgasm. It may cause some discomfort at first, but this usually improves with time. You may pass a small amount of urine when you orgasm. Talk to your urologist or specialist nurse if you are having this problem. They may be able to give you some advice.

Infertility

Having your prostate removed will affect your fertility. This is your ability to make someone pregnant. The prostate and seminal vesicles produce semen, which is normally mixed with sperm from the testicles. Removing the prostate means you will not be able to ejaculate anymore.

It is important to talk to your urologist or specialist nurse about fertility before treatment. It may be possible to store sperm before your surgery. We have more information about fertility in our booklet Cancer and fertility.

Bladder problems

It is usual to have some leaking from the bladder when the catheter is first removed. This is called urinary incontinence. It usually improves within a few weeks or months after surgery. You will be encouraged to do pelvic floor exercises to strengthen the pelvic floor muscles. You will need to wear a pad to manage the incontinence, but the need for pads should lessen.

You can find out more about pelvic floor exercises on our website at macmillan.org.uk/pelvic-floor-exercises

Sometimes, you may have some incontinence when you cough, sneeze or exercise. This is called stress incontinence. It is rare to be completely incontinent, but it can happen. If you are having problems, talk to your GP, urologist or specialist nurse. They can refer you to a continence specialist who can give you treatment, information and support to manage your symptoms. If these do not help, you may be able to have surgery to improve your symptoms.

Another less common side effect can be scarring to the urethra or the entrance of the bladder. This is called the bladder neck. Scar tissue can narrow the bladder neck or the urethra and make passing urine difficult. This causes urine to build up in the bladder and overflow, causing you to leak urine. This can usually be treated with a small operation that opens up the bladder neck or the urethra. If you are having problems passing urine after surgery, talk to your GP, urologist or specialist nurse.

> **"After the surgery, I had some incontinence, because I had to get used to going to the toilet more often. I think it was caused by the weak pelvic muscle. I had read about this. I'd also read about the impotence, which I had."**
>
> Sean, diagnosed with prostate cancer

Macmillan toilet card

If you need to use a toilet urgently, Macmillan has a toilet card that you can use in places such as shops, offices, cafés and pubs. You can use it during or after treatment. We hope it allows you to get access to a toilet without any awkward questions. But we cannot guarantee that it will work everywhere.

You can order the Macmillan toilet card from our website, at orders.macmillan.org.uk

Transurethral resection of the prostate (TURP)

Your surgeon may offer you a transurethral resection of the prostate (TURP) if you are having difficulty passing urine (peeing). A TURP is not done to treat the cancer.

The prostate gland surrounds the urethra, the tube that drains urine from the bladder. If the prostate cancer starts to press on the urethra, it can restrict the flow of urine. The aim of the surgery is to remove the area of prostate that is pressing on the urethra. It can help you pass urine more easily again and improve symptoms.

You may have a TURP before radiotherapy. This is because radiotherapy can make passing urine more difficult during and for a while after treatment.

Having a TURP

Before surgery, you may have a pre-operative assessment. This may involve having some tests to check your general health and fitness. We have more information about this on our website at macmillan.org.uk/preparing-surgery

A TURP can be done under a general anaesthetic (where you are asleep). Or you may have a spinal anaesthetic, which is an injection of anaesthetic around the spine. We have more information about types of anaesthetic.

During a TURP, the surgeon passes a thin tube through the urethra into the prostate. This tube has a cutting instrument and tiny camera. The surgeon uses the cutting instrument to shave off the inner area of the prostate. These pieces of prostate are sent to the laboratory to be tested.

A TURP can also be done using a special laser to remove the inner area of the prostate. This is only done in some specialist treatment centres. Your surgeon will advise you if this is suitable for you.

You usually go into hospital on the day of your surgery, or the day before.

The nurse will give you compression stockings to put on. These are called TED stockings. You will also have to wear these for a period of time after surgery. Compression stockings reduce the risk of getting a blood clot in your legs. This is called deep vein thrombosis or DVT.

After your TURP

If you are having a general anaesthetic, your surgeon, anaesthetist or nurse will explain what to expect when you wake up after surgery.

Immediately after surgery, the nurses can help you with washing and going to the toilet. But they will encourage you to be up and moving around as soon as possible. They can help you move safely with your catheter. You may feel anxious about this, but moving around prevents complications and helps your recovery.

You will usually have a drip into a vein in your arm (intravenous infusion). This will stay in for a few hours after your operation, until you are eating and drinking again.

You can usually go home 3 or 4 days after a TURP. We have more information about what to expect after surgery on our website at macmillan.org.uk/after-surgery

Urinary catheter

During surgery, you will have a tube put in your urethra. This tube drains urine from your bladder. It is called a catheter. The catheter keeps your bladder empty while the prostate and urethra heal. Try to drink plenty of fluids to help keep the catheter draining well.

For a while after a TURP, your urine will have blood in it. To stop blood clots blocking the catheter, fluid is passed into the bladder and drained out through the catheter. This is called bladder irrigation. It helps to wash out the bladder. The blood will slowly clear from your urine and then the catheter can be taken out.

You may still get the feeling that you want to pass urine (pee) when the catheter is in. This is called a bladder spasm. Sometimes you leak urine around the catheter when this happens. These spasms are normal but can be uncomfortable. If they last a long time and happen often, tell your nurses on the ward.

You may need the catheter for a while after you go home. This is because swelling caused by the surgery may make it difficult for you to pass urine.

The nurses on the ward will show you how to look after your catheter before you go home. They will give you spare bags to take home. If you need more support, they can arrange for a district or community nurse to visit you at home.

When the catheter is first removed, you may find it difficult to pass urine. This will improve. You may see blood in your urine for 24 to 48 hours, but it should start to clear. There may be some old bits of dried blood clot after 7 to 10 days. Drinking plenty of fluids can help.

If you cannot pass urine after your catheter has been removed, call the number you have been given straight away or go straight to the emergency department (A&E) at the hospital. You may need another catheter for a couple of days before it can be removed again.

You may leak urine after a TURP. This is called urinary incontinence. It usually improves within a few weeks. You may need to wear a pad until it improves. You may notice that you want to pass urine more urgently or frequently for a while too.

Preventing blood clots

After your surgery, the nurses will encourage you to get up and move around. This is to help prevent complications such as blood clots in the veins in the legs. You will continue to wear your compression stockings (TED stocking) to help prevent clots. Your nurse can explain how to wash and care for them. They may give you a spare pair to take home. They can advise you when you no longer need to wear the stockings.

Side effects of a TURP

There are some side effects after having a TURP. Some side effects improve over time, but some are permanent.

Pain

You may have pain and discomfort for a few days after your operation. You will be given painkillers to help with this. In hospital, you may have painkillers through a drip (infusion) in your vein, or by injection. This will then be replaced with painkiller tablets. Tell the nurses on the ward if you are still in pain. They will give you tablets to take home with you and explain how to take them.

If at any time you have burning or stinging when you pass urine tell your cancer team. They may check to see if you have a urine infection.

Ejaculating into the bladder

Ejaculating into the bladder is called retrograde ejaculation. It is caused by damage to the nerves or muscles that surround the bladder neck. This is where the urethra joins the bladder. During retrograde ejaculation, semen goes backwards into the bladder instead of through the urethra in the normal way. After retrograde ejaculation, your urine may look cloudy. This is because there is semen in the bladder. It is harmless.

Erection problems

Having a TURP can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). It might depend on whether you had problems getting an erection before surgery. Your surgeon can tell you more about your risk of erection problems. Your surgeon or specialist nurse can also give you information and support.

Difficulty passing urine

Sometimes TURP can cause long term difficulties with passing urine. Talk to your urologist or specialist nurse if you are having problems. They can offer help and support and may arrange some tests.

Going home

You can usually go home 3 or 4 days after a TURP.

Before you leave hospital, your hospital doctor will send a letter called a discharge summary to your GP. The letter is usually sent electronically so that your GP gets it within 24 hours of your discharge. You are usually given a copy to take home with you. It will explain what type of surgery you had, any medication you are taking and about your follow-up care.

If you need a district or community nurse, the ward nurses will organise this before you go home. You should also be given 24-hour telephone numbers for your hospital team in case you need to contact them.

Your surgeon, specialist nurse or nurses on the ward can give you advice on when you can start doing things such as driving or returning to work. They can also give you advice on when you can have sex again. We have more information about sex and prostate cancer on our website at macmillan.org.uk/sex-prostate-cancer

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website at macmillan.org.uk/clinical-trials

Taking part in a clinical trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

After treatment

Follow-up after treatment 102
Wellbeing and recovery 106
Sex 109
Fertility 117
Relationships and sex 119

Follow-up after treatment

After treatment ends, you will have follow-up appointments. Your urologist, cancer doctor or specialist nurse will talk to you about the type of follow-up you will have. Follow-up appointments will be at the hospital to start with. After a while, the appointments may be over the phone.

Depending on the system your hospital uses, you may be asked to review your PSA result online. Your specialist nurse can explain which type of online site your hospital uses. They will show you how to get started and use the system. Or you may be able to review it on the NHS app on your smartphone. You can contact your specialist nurse any time if you have questions.

If you had treatment to cure prostate cancer, you have regular check-ups every few months for the first year. These continue for several years depending on your situation but with longer gaps between appointments.

During a follow-up visit, your doctor or specialist nurse will usually ask questions about the side effects of treatment and whether you have any changes with your bowel, bladder or erections.

It can sometimes feel embarrassing to talk about these kinds of problems, but your doctor and specialist nurse are used to talking about them every day. They would rather know so they can offer you the right information and support. They can suggest treatments or refer you to other specialists who can help. You do not need to use medical words. Use the words you usually use so they can understand your concerns.

You might find it helpful to write down any questions before your appointment. It can also help to bring someone with you, or have someone listen if the appointment is by phone. They can help you remember what was said or take notes.

You should be given a copy of the letter the doctor or specialist nurse writes after your appointments.

If you have questions or concerns between appointments, you can call your specialist nurse for information and support.

We have more information about:

- talking to your healthcare team and asking questions – macmillan.org.uk/talk-healthcare-team
- support to understand information – macmillan.org.uk/understanding-information

Monitoring your PSA level

You will not have your PSA level checked until 6 weeks after you finish treatment. After this you may have it tested every 3 to 6 months for the first few years, then every 6 to 12 months. Your cancer doctor and specialist nurse can tell you how often it will be checked.

You will usually have a PSA test 1 to 2 weeks before your follow-up appointment, so your doctor can check the results. You do not usually need a rectal examination unless your PSA level rises.

Your PSA level tells doctors how well treatments are working.

If prostate cancer comes back, the first sign is usually a rise in the PSA level. You usually need more than 1 rise in the PSA level to find out whether prostate cancer has come back. Doctors also check how quickly it rises.

Symptoms

It can also be helpful to be aware of symptoms you may get. Symptoms may be linked to long term or late side effects of treatment. We have more information about this on our website at macmillan.org.uk/late-effects-of-treatment

Do not wait until your appointment to report any new symptoms or symptoms that do not go away. Tell your urologist, cancer doctor or specialist nurse about them immediately. For example, these symptoms may include:

- urinary or bowel symptoms (including bleeding from the bladder or anus)
- pain in any area of the bones
- any changes in feeling, or loss of strength in your legs.

You may find you feel anxious before your clinic appointments. This is natural. It may help to get support from family or friends , or a support organisation. You can also call the free Macmillan Support Line on 0808 808 00 00.

If prostate cancer comes back

Treatments may cure locally advanced prostate cancer. But sometimes the cancer may come back. If this happens, you can usually have further treatment. This will depend on the treatment you have already had and where the cancer comes back. Your doctor can explain what treatment might be right for your situation. They will ask you to contact them if you have symptoms. These can include:

- losing weight when you are not trying
- loss of appetite
- feeling extremely tired (fatigue)
- bone pain, especially in your back
- bladder or bowel problems or blood in your pee (urine) or semen
- swelling in your feet and legs.

You can contact your cancer team if you have any questions or concerns about symptoms.

Wellbeing and recovery

Even if you already have a healthy lifestyle, you may choose to make some lifestyle changes after treatment. Making small changes can improve your health and wellbeing. It can help your body recover and to manage some side effects. It may also help reduce the risk of other illnesses, such as heart disease and strokes.

Eat healthily

Eating a healthy diet and keeping to a healthy weight reduces the risk of heart problems, diabetes and developing some other cancers. Your GP and specialist nurse can advise you and give you information about your ideal weight. Try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less saturated fat and less sugar
- become more physically active.

Keep active

Being physically active will help you keep to a healthy weight and can reduce stress and tiredness. It also helps keep your bones strong and your heart healthy.

You might find these booklets helpful:

- Healthy eating and cancer
- Heart health and cancer treatment
- Diabetes and cancer treatment
- Physical activity and cancer
- Bone health and cancer treatment.

> "After my treatment, I signed up to a local gym so I could build up my strength again. I have managed to get back to hill walking. „

Willie, diagnosed with prostate cancer

Stop smoking

Stopping smoking is one of the healthiest decisions anyone can make. Smoking increases the risk of bone thinning (osteoporosis) and is a major risk factor for smoking-related cancers and heart disease.

We have more information about stopping smoking on our website at macmillan.org.uk/stop-smoking

Look after your bones

Hormonal therapy for prostate cancer can increase the risk of bone thinning (osteoporosis). Keeping physically active and eating a healthy diet with enough calcium and vitamin D helps keep your bones healthy. We have more information about bone health in our booklet Bone health and cancer treatment. Smoking can also increase your risk of bone thinning.

Drink less alcohol

Drinking guidelines recommend no more than 14 units of alcohol a week. Try to also have a few alcohol-free days each week. One unit is:

- half a pint of ordinary-strength beer, lager or cider
- a small glass (125ml) of wine
- a single measure (25ml) of spirits.

Drinkaware has more information about alcohol and drinking guidelines. Visit drinkaware.co.uk

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Sex

Treatments for prostate cancer can cause sexual difficulties and make you feel less interested in sex. These side effects can include:

- tiredness (fatigue)
- feeling less interested in sex (loss of libido)
- changes to your bladder or bowel
- hormonal effects, such as weight gain or breast swelling.

As side effects improve, you may feel more interested in sex.

If prostate cancer and its treatments are affecting your sexual wellbeing, it can feel very difficult to cope with. You do not need to be in a relationship to feel this. But there are different ways to manage sexual difficulties.

Cancer and its treatments can also affect how you feel and think about your body (body image). You may feel less sexually attractive. If you are having issues with your body image, ask your GP, cancer doctor or specialist nurse for advice. We also have more information about body image in our booklet Body image and cancer.

Certain lifestyle changes may help improve body image concerns, such as being more physically active, eating healthily, and managing your weight. Ask your GP, cancer doctor or specialist nurse for advice. We also have more information in our booklets Physical activity and cancer and Healthy eating and cancer.

Sexual difficulties

Prostate cancer treatments can have a direct effect on your sexual wellbeing. For example, they can cause difficulty with getting or keeping an erection. This is called erectile dysfunction (ED). We have more information about ED on our website at macmillan.org.uk/erection-problems

You may already have had sexual difficulties before your diagnosis. These become more common as you get older. ED is also linked with conditions such as high blood pressure and raised cholesterol.

Cancer treatments can cause difficulties getting or keeping an erection. After a radical prostatectomy, ED may happen soon after treatment.

With radiotherapy, you may not have ED problems immediately after treatment, but it may develop over years. Hormonal therapy may also lower your ability to get and maintain an erection. Your erections may improve slowly over a few months after stopping hormonal therapy.

Treatment can also affect your ability to have an orgasm or to ejaculate. After a radical prostatectomy, you will not ejaculate semen but can still have an orgasm. After having external radiotherapy or brachytherapy, you do not usually produce much semen but can still orgasm.

Some treatments can reduce your sex drive (libido). Hormonal therapy, which you may have with radiotherapy, lowers your libido.

If you have ED, there are different treatments to help you.

> "My sexual function hasn't returned to a great level, but has been manageable with medication. The limited sensation this gave me actually improved my self-confidence and mental state more than it did my sex life."

Simon, diagnosed with prostate cancer

Talking about sex

You may find it difficult to talk about sex with your GP, urologist, cancer doctor or specialist nurse. But it is important to have your questions answered and to get the help you need. They should make you feel comfortable during conversations about sex. You do not need to use medical words. Use the words you normally use. This can help the professionals understand how to best support you.

You may want to think about if there is someone in your healthcare team you feel more comfortable talking to. To help you feel prepared, plan what you want to say in advance and write down your questions. If you have a partner, you may want them with you at these discussions. Or you may prefer to talk confidentially with your doctor or nurse. If you need more specialist advice your GP, urologist, cancer doctor or specialist nurse can refer you to an ED clinic or a sex therapist.

If you find it difficult talking to your healthcare team or getting information, there is support available. Visit macmillan.org.uk/understanding-information You can talk in confidence to a cancer information nurse specialist on our Macmillan Support Line or through email. Prostate Cancer UK also has a helpline where you can talk or chat online to a specialist prostate nurse.

Sex and treatment

If you have questions about sex during or after treatment, ask your urologist, cancer doctor or specialist nurse. Having sex will not affect how well your treatment works. In some situations, they may advise you to be cautious about sex during treatment or immediately after it finishes. For example, after surgery you may be advised to wait until your wound has healed. Side effects of pelvic radiotherapy, such as skin changes or tiredness, may make having sex difficult or you just might not feel ready. You may decide to wait until your side effects improve.

If you identify as LGBTQ+

Your healthcare team is there to support you and treat you in a way you feel comfortable with. There may be times when it helps if the team know how you identify your gender or sexual orientation. It may help you feel better supported. And your healthcare team can give the right information and support to you and your partner, if you have one.

The impact of cancer and cancer treatment are often the same whatever your sexual orientation or gender. But you may have some specific questions about how these will affect your sexual wellbeing. We have more information on our website at macmillan.org.uk/lgbtq-cancer

If you are trans (transgender) or non-binary, talking to a healthcare professional about sex can sometimes be especially difficult and complicated. Some of the information you need may involve parts of the body that do not reflect your gender identity. You may find this uncomfortable or upsetting to talk about. You may also have specific questions about sex and cancer if you take hormones or have had gender realignment surgeries.

If you do not feel you can talk to your healthcare team, you could talk to:

- your local sexual health service
- a transgender sexual health service.

We have more information about this on our website at macmillan.org.uk/trans-and-non-binary

Prostate Cancer UK has more information for gay and bisexual men and transgender women.

If your healthcare team cannot help, they can refer you to a sex therapist or another specialist. If you want to talk things through, you can call the LGBT Foundation on 03453 30 30 30. They can give you confidential advice and support.

Prostate cancer treatment and anal sex

Pelvic radiotherapy can affect the lower bowel (rectum) and cause side effects. If you receive anal sex, your healthcare team may advise you to wait until 8 weeks after treatment. This avoids making side effect worse or causing longer term problems. Your cancer doctor, radiographer or specialist nurse can explain when it should be safe to receive anal sex. You can talk to them about long term changes to the rectum that may make receiving anal sex difficult.

After a radical prostatectomy, you are usually advised to wait for 6 weeks before you receive anal sex. Your urologist or specialist nurse can talk to you about when it should be safe.

When you feel ready to try, start slowly and gently. Use lubricant to help protect the anus and rectum. Take your time and build up to full penetration slowly.

Managing erectile dysfunction (ED)

There are practical ways to help manage ED. Your urologist, cancer doctor or specialist nurse can give you information about these.

If you are having hormonal therapy, it is likely to lower your sex drive. Treatments for ED do not increase sex drive, but you may still want to try them.

Penile rehabilitation

Penile rehabilitation means using erectile dysfunction (ED) treatments to reduce the risk of long term erection problems after pelvic surgery or radiotherapy. Because a radical prostatectomy can cause ED problems quickly, you may be offered penile rehabilitation soon after treatment.

After cancer treatment, you have ED treatments and use a vacuum pump regularly. You do this even if you do not want an erection or to have sex. This is to exercise the muscles and tissues needed for erections. This may improve the chance of being able to have erections.

Using ED treatments in this way is not always available through the NHS. There is not enough evidence to show how effective it is yet.

Your urologist, cancer doctor or specialist nurse can tell you more about this.

Treatments for ED

Most ED treatments aim to increase the blood supply to the penis. You may need to try a treatment a few times to start with. You may want to try more than one method. Your urologist, cancer doctor or specialist nurse can give you advice and support.

Treatments for ED include:

- tablets
- injections
- pellets or creams
- pumps.

These all work by improving the blood flow to the penis. Your healthcare team can tell you more about these methods if they are suitable for you. They can explain how to use them and about any side effects.

If other treatments do not work for you, your healthcare team may talk to you about penile implants. These are not always available through the NHS.

You may also be able to improve erections with lifestyle changes such as keeping to a healthy weight and being physically active. Other things that can help are finding ways to cope with stress, stopping smoking, drinking less alcohol and not taking recreational drugs.

We have information about these methods online at macmillan.org.uk/sex-and-cancer You can also listen to stories from people who have had a radical prostatectomy and the effect on their sex life.

You may also find it helpful to read our booklet, Cancer and your sex life.

Fertility

Most treatments for prostate cancer are likely to cause infertility. This means you will no longer be able to get someone pregnant naturally. We have more information about fertility in our booklet Cancer and fertility.

If fertility is a concern for you, talk to your specialist before treatment. It is usually possible to store sperm before treatment starts, but you may need to pay for this. The sperm may then be used later as part of fertility treatment.

> " My strength came from my wife and family. I could not have gotten through what I've gone through without that help and that network. "
>
> Errol

Relationships and sex

If you have a partner, talking openly with them can help you feel closer. It can also help you make changes to your sex life together. Talking about things can help you avoid misunderstandings and find ways to cope with problems.

There are different ways you can show your partner you care about them. This can include spending time together and showing affection through touching, holding hands or putting an arm around them.

Remember, there are lots of ways to give and receive pleasure. You do not need to be able to have penetrative sex to make a partner feel good. And you do not always need to have an erection to ejaculate or have an orgasm.

You could try other types of touching, such as oral sex or using sex toys. Take time to try new things and experiment to find what feels good now. A sex therapist may be able to help you cope or find different ways to enjoy sex or improve your sexual wellbeing.

Talking to a counsellor or sex therapist may help you and your partner adapt to changes in your sex life. You can ask your partner to come to appointments with you. This will help them understand the issues you are dealing with.

If you are not in a relationship, it is natural to worry about meeting a new partner or about your sex life. You may need some time to come to terms with what has happened. It may help to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists has a list of nationwide counsellors and therapists who can offer advice and support.

Your feelings and relationships

Your feelings 122

Relationships 123

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions:

- in our booklet and audiobook How are you feeling? The emotional effects of cancer
- on our website at macmillan.org.uk/emotions

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends (also available as an audiobook).

We also have more information online at macmillan.org.uk/relationships

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone in our booklet and audiobook Talking with someone who has cancer.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers:

- in our booklet and audiobook Looking after someone with cancer
- on our website at macmillan.org.uk/carers

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet and audiobook Talking to children and teenagers when an adult has cancer.


CAB

Financial support and work

Help with money and benefits 128

Work 131

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information about Statutory Sick Pay and benefits you may be entitled to on our website. Visit macmillan.org.uk/sick-pay

We also have information for carers at macmillan.org.uk/carers

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits, and recommend other useful organisations that can help. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet and audiobook Help with the cost of cancer has lots more information.

Grants

You may be able to get some financial help from other charities – for example, one-off grants. For further information, contact the Macmillan Support Line on 0808 808 00 00.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our booklet and audiobook Travel and cancer.

Our Online Community forum on travel insurance may also be helpful. Visit macmillan.org.uk/community

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets have more information that may be helpful:

- Work and cancer
- Working while caring for someone with cancer
- Self-employment and cancer.

You can find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

Further information

About our information 134

Other ways we can help you 136

Other useful organisations 140

Your notes and questions 152

About our information

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

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

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

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

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

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

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Help with work and cancer

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Prostate cancer support organisations

Bladder and Bowel Community

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

infopool

Tel **0203 735 5444**
www.theinfopool.co.uk
An online resource about prostate cancer created by Prostate Cancer Research and co-designed with patients and clinicians. It has information about treatments and tests, as well as stories from people affected by prostate cancer.

Orchid

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

Predict Prostate

prostate.predict.cam
A tool designed to help people diagnosed with prostate cancer better understand their treatment options.

Prostate Cancer UK

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

Prostate Scotland

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

Tackle Prostate Cancer

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

Sex and relationship support

Prostate Cancer UK sexual support service

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

Sexual Advice Association

www.sexualadviceassociation.co.uk
Aims to improve the sexual health and wellbeing of men and women, and to raise awareness of how sexual conditions affect the general population.

General cancer support organisations

Cancer Black Care

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

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Macmillan Cancer Voices

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

Maggie's

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

Penny Brohn UK

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

Tenovus

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

General health information

Drinkaware

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

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

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

NHS Inform

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

Patient UK

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

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way (Scotland)

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 085 2219 0808 278 6119**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

College of Sexual and Relationship Therapists (COSRT)

Tel **0208 106 9635**
www.cosrt.org.uk
Provides information about sexual well-being, including having therapy and finding a therapist. Has a list of professional therapists on the website.

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Support for older people

Age UK

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

Support for LGBTQ+ people

LGBT Foundation

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

Out with Prostate Cancer

Tel **0794 488 6043**
www.outwithprostatecancer.org.uk
A prostate cancer support group directed primarily at gay and bisexual men, trans women and non-binary people. Offers support and practical information to those diagnosed with prostate cancer.

OUTpatients

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

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Disclaimer

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

Thanks

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

With thanks to:

Professor Alison Birtle, Consultant Clinical Oncologist; J. Sharon Clovis, Prostate Clinical Nurse Specialist; Dr Denis Colligan, General Practitioner; Professor Duncan McLaren, Consultant Clinical Oncologist; Mr Vinod Nargund, Consultant Urologist; Anthony Shanahan, Senior Advanced Clinical Practitioner in Urology; Harley Stephens, Consultant Therapeutic Radiographer; Mr Werner Struss, Consultant Urological Surgeon; and Paolo Zabat, Advanced Nurse Practitioner.

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

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

Sources

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

National Institute for Health and Care Excellence (NICE). Prostate cancer: diagnosis and management. NICE Guideline [NG131]. Published: 09 May 2019. Last updated: 15 December 2021. Available from: www.nice.org.uk/guidance/ng131 [accessed March 2024].

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

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

FR Registered with FUNDRAISING REGULATOR

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

MACMILLAN
CANCER SUPPORT

This booklet is about locally advanced prostate cancer. It is for anyone who has been diagnosed with locally advanced prostate cancer. There is also information for carers, family members and friends.

The booklet explains how locally advanced prostate cancer may be treated. It also has information about feelings, practical issues and money.

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

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

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

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

Trusted
Information
Creator
Patient Information Forum