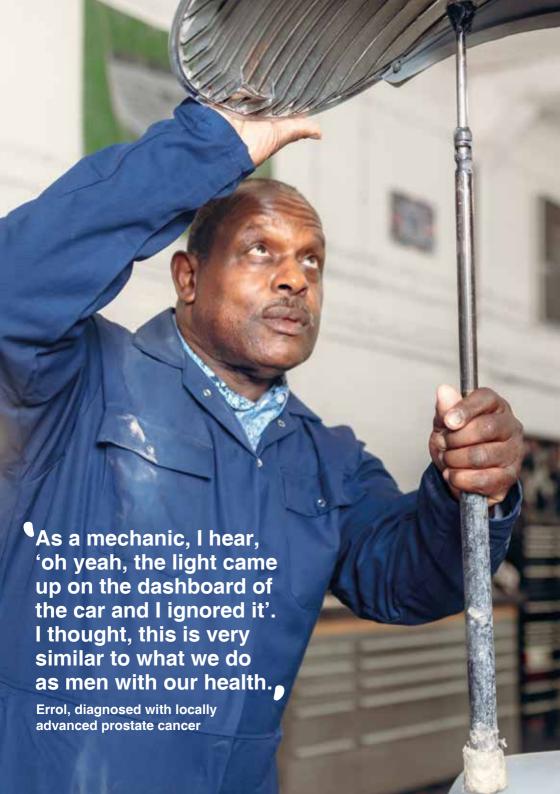
MACMILLAN CANCER SUPPORT

# UNDERSTANDING LOCALLY ADVANCED PROSTATE CANCER





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 family members and friends.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk** 

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# MACMILLAN CANCER SUPPORT

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#### About this booklet

This booklet is for anyone who has been diagnosed with locally advanced prostate cancer. This is when the cancer has grown through the capsule surrounding the prostate. It may have started to spread into tissue or organs close by. There is also information for family members, carers and friends.

The booklet explains the different treatments for locally advanced prostate cancer and their side effects. It also has information about the feelings you might experience, and how your relationships, work and finances might be affected

This booklet does not have information about prostate cancer that has spread to other parts of the body. We have another booklet about this called **Understanding advanced** (metastatic) prostate cancer – see page 122.

We hope it helps you deal with some of the questions or feelings you may have.

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 on page 3 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 127 to 135, there are details of other organisations that can help.

#### Quotes

In this booklet, we have included guotes from people who have had locally advanced prostate cancer, which you may find helpful. This includes Errol, who is on the cover of this booklet. These are from people who have chosen to share their story with us. Toshare 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.

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121

# **Contents**

About prostate cancer

**Further information** 

Prostate cancer staging	16
Treating locally advanced prostate cancer	27
After treatment	84
Your feelings and relationships	103
Financial support and work	112



# ABOUT PROSTATE CANCER

What is cancer?	6
The lymphatic system	8
The prostate	9
Locally advanced prostate cancer	11
Risk factors and causes	13

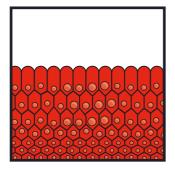
#### What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

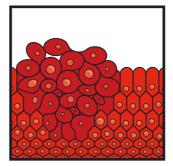
Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

#### 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 of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 8). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

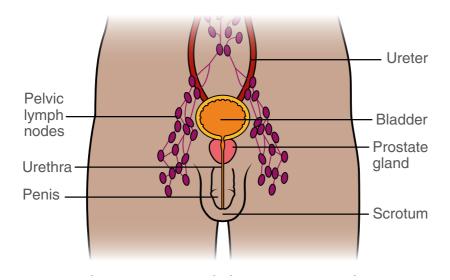
# The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

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

Some locally advanced prostate cancer may have spread to the lymph nodes that are close to the prostate (see pages 19 to 23).

#### Prostate lymph nodes



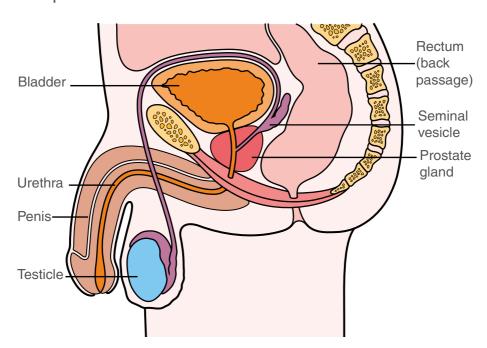
### The prostate

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 pee (urine) from the bladder to the penis. The same tube also carries semen, which is the fluid containing sperm. Just behind the prostate is the back passage (rectum). There are also lymph nodes (sometimes called glands) near the prostate.

The prostate contains muscle tissue and glandular tissue. Glandular tissue releases (secretes) certain substances.

#### 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. They are found just behind the bladder. During sex, the muscle tissue helps force (ejaculate) prostate fluid and sperm into the urethra.

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

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen more watery. A blood test can measure PSA. This is called a PSA test. Doctors use it to help diagnose different prostate problems, including cancer. We have more information about the PSA test on our website (see page 122).

#### If you are a transgender woman

People who have a prostate include men, transgender (trans) 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.

# Locally advanced prostate cancer

Prostate cancer is the most common cancer in men in the UK. About 48,600 men are diagnosed with it each year. It is more common over the age of 65. Although it can happen at a younger age, it is uncommon under the age of 50. There is a higher risk of getting prostate cancer at a younger are if you are Black or have a strong family history of prostate cancer (see pages 13 to 15).

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 if it is locally advanced.

If you are a trans woman or are non-binary or assigned male at birth, you also need to be aware of prostate cancer. Prostate cancer may affect trans women, but there is not enough evidence to know how common this is.

Prostate Cancer UK has more detailed information about trans women and prostate cancer (see page 127). The LGBT Foundation can also give you confidential advice and support (see page 134). You can also talk to one of our cancer support specialists (see page 124).

We have more information about test for prostate cancer in our booklet **Having tests for prostate cancer** and on our website (see page 122).



#### Risk factors and causes

Doctors do not know the exact causes of prostate cancer. But there are risk factors that can increase the chance of getting it. Having one or more risk factors does not mean you will get prostate cancer. There are different risk factors that may affect the risk of getting prostate cancer.

#### Age

This is the strongest risk factor for prostate cancer and your risk increases from the age of 50. It is uncommon under the age of 50 and more common over the age of 75. Risk factors like ethnicity and family history are linked with getting prostate cancer at a younger age.

#### **Ethnicity**

If you are Black, you have a much higher risk of developing prostate cancer. The reason for this is not clear, but it may be because of genetic factors. You are also more likely to develop prostate cancer at a younger age.

If you are Black and aged 45 or over, Prostate Cancer UK has more information about your risk. It gives advice on talking to your GP about your risk of getting prostate cancer and helps you to make decisions about having a PSA test. See page 127 for contact details. We also have more information about ethnicity and the PSA test on our website (see page 122).

If you are Asian, your risk of prostate cancer is much lower. We do not know why this is.

#### Family history

Sometimes there may be a possible family link (inherited). The risk of prostate cancer is higher if you have:

- either a father or brother who had prostate cancer the risk is greater if they were diagnosed under the age of 60
- 2 or more close relatives (father, brother, grandfather, half-brother, uncle) on the same side of the family who had prostate cancer
- a mother who had breast cancer
- inherited certain cancer gene changes (mutations).

We get a copy of each of our genes from both parents. Genes are the instructions that tell our cells what to do. Doctors think 5 to 10 out of 100 prostate cancers (5% to 10%) are linked to inherited gene changes.

Rarely, prostate cancer may be linked to changes in certain genes. They are called BRCA1 and BRCA2. These altered genes increase the risk of breast and ovarian cancer in women. If you have inherited the BRCA2 gene change, your risk of prostate cancer is 5 times higher. The BRCA1 gene may also increase your risk, but this is not as clear.

Prostate cancer risk is also higher if you have Lynch syndrome. Lynch syndrome is also called hereditary non-polyposis colorectal cancer (HNPCC). Lynch syndrome is rare but can increase the risk of a number of cancers. We have more information about Lynch syndrome on our website (see page 122).

Talk to your GP if you have a family history of cancer and are worried about your risk of prostate cancer. We have more information about family history and cancer in our booklet Cancer genetics - how cancer sometimes runs in families (see page 122).

#### **Body weight and diet**

Being very overweight (obese) may increase the risk of having a more advanced prostate cancer. It may also increase the risk of having a faster-growing type of prostate cancer.

Eating a balanced diet and doing regular physical activity will keep you to a healthy weight.

# PROSTATE CANCER STAGING

Risk groups	18
Stage, Gleason score and Grade Group	19
Gleason score and Grade Group	22
Your data and the cancer registry	24



# Risk groups

Prostate cancer is divided into risk groups. Before planning your treatment, your cancer doctor will look closely at your risk group. This helps you and your doctors to decide on the best treatment for you. Locally advanced prostate cancer may also be called high-risk prostate cancer.

To work out your risk group, your doctors look at:

- your PSA level
- your Gleason score the pattern of the prostate cells and how they compare with normal prostate cells (see pages 22 to 23)
- the stage of the cancer the size of the tumour and how far it has spread (see pages 19 to 21).

High-risk prostate cancer has any one of the following:

- a PSA level of over 20
- a Gleason score of 8 to 10
- is stage T2c, T3 or T4.

Some cancers that are contained in the prostate gland are described as locally advanced.

You can read more about the stage and Gleason score (see pages 19 to 21). There is also a grading system based on your Gleason score, called your Grade Group (see pages 22 to 23).

# Stage, Gleason score and Grade Group

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

Doctors often use the TNM staging system or a number staging system for prostate cancer.

#### TNM staging system

This gives information about:

- the tumour (T)
- whether the cancer has spread to any lymph nodes (N)
- whether the cancer has spread to another part of the body, called metastasis (M).

#### **Tumour**

Doctors put a number next to the T to describe the size and spread of the cancer.

T1 and T2 tumours are called early (localised) prostate cancer. They are contained in the prostate. T2 tumours are sub divided depending whether they are in one or both lobes of the prostate. For example, T2c is in both lobes of the prostate.

T3 tumours have spread outside the prostate and may be growing into tissues close by:

- T3a the tumour has spread through the capsule surrounding the prostate.
- T3b the tumour has spread to the seminal vesicles that produce the fluid for semen.

T4 tumours have spread into areas close by, such as the bladder or back passage (rectum), or the muscle that controls peeing (passing urine).

T3 and T4 cancers are called locally advanced prostate cancer.

#### **Nodes**

N0 means there is no cancer in the lymph nodes near the prostate.

N1 means there is cancer in 1 or more lymph nodes close by.

#### Metastasis

M0 means the cancer has not spread to another part of the body, so locally advanced prostate cancer is always M0.

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

#### **Number staging system**

Number staging brings together different parts of the TNM staging system and gives it a number stage. Locally advanced prostate cancer is stage 3, or sometimes stage 4.

#### Stage 3

Stage 3 is any T3 tumour when the cancer has not spread to the lymph nodes or to another part of the body.

#### Stage 4

Stage 4 is any T4 tumour that either:

- · has not spread to the lymph nodes
- has spread to the lymph nodes close by and is any size.

This is called locally advanced prostate cancer.

Stage 4 is also any tumour that has spread to another part of the body, such as the bones. This is called advanced or metastatic prostate cancer.

# Gleason score and Grade Group

A doctor decides the grade of the cancer by how the cancer cells look under the microscope. This information comes from your biopsy results.

The grade gives an idea of how quickly the cancer might grow or spread. Doctors use a combination of 2 systems to grade the cancer. These are called:

- Gleason score
- Grade Group.

#### Gleason score

This examines the pattern of cancer cells in the prostate tissue, and how they look and act, compared with normal cells.

There are 5 different patterns, graded from 1 to 5. Grade 1 and 2 looks like normal prostate tissue. But grade 5 is very different to normal tissue.

There may be more than 1 grade. The doctor examines all the biopsy samples taken and decides on:

- the most common grade
- the highest grade.

They add these together to give your Gleason score. A Gleason score of 7 could be:

 3 + 4 – the most common grade is 3 and the highest grade is 4

or

• 4 + 3 – the most common and highest grade are both 4, but there is also some grade 3 present.

#### What your Gleason score means

If your Gleason score is between 6 and 10, the cancer is:

- Gleason score 6 slow growing
- Gleason score 7 intermediate grade (between slow and fast-growing)
- Gleason score 8 to 10 high grade (more likely to grow quickly).

#### Grade Group

This grades the cancer between 1 and 5 based on your Gleason score. The lower the Grade Group the less likely the cancer is to grow and spread.

There are 5 Grade Groups:

- Group 1 Gleason score 6
- Group 2 Gleason score 7 (3+4)
- Group 3 Gleason score 7 (4+3)
- Group 4 Gleason score 8
- Group 5 Gleason scores 9 to 10.

If you are in Group 3, where the highest grade is most common, you may need more treatment than Group 2.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

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





# TREATING LOCALLY ADVANCED PROSTATE CANCER

Treatment overview	28
Radiotherapy	38
Hormonal therapy	54
Watchful waiting	62
Surgery	63
Chemotherapy	78
Clinical trials	80

#### Treatment overview

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

Your doctor and nurse will help you understand what these treatments involve and how they may affect your life. If possible, you may want to involve a partner or someone close to you in these discussions. Making treatment decisions can be difficult, but there is support to help you.

Your treatment will depend on:

- your general health
- your age
- the Gleason score and cancer grade (see pages 22 to 23)
- the stage of the cancer (see pages 19 to 21)
- your preferences.

Your doctor will talk to you about the different things to think about when making treatment decisions. They will explain the different benefits and disadvantages of each treatment. You and your doctor 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.

#### **Treatments**

The main treatments include hormonal therapy, radiotherapy, and watchful waiting. You may need a combination of treatments. Sometimes your doctor may talk to you about having your treatment as part of a clinical trial (see pages 80 to 83).

#### Radiotherapy

Radiotherapy uses high-energy x-rays to destroy the cancer cells. It is often the main treatment for locally advanced prostate cancer (see pages 38 to 53).

It is usually given externally (from outside the body). You may have internal radiotherapy (brachytherapy) as well – see pages 50 to 53. You usually have radiotherapy with hormonal therapy - see pages 54 to 61.

It is not common to have the prostate removed with surgery (radical prostatectomy) – see pages 63 to 76. If you do, you may need radiotherapy after it.

#### Hormonal therapy

Prostate cancer needs testosterone to grow. Hormonal therapies reduce the amount of testosterone in the body. You may have hormonal therapy with radiotherapy to make treatment more effective. Or 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 make would make it difficult.

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

#### 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. Doctors call this watchful waiting (watch and wait).

You do not have regular scans or start treatment unless the cancer is changing, or you get symptoms. It means you avoid treatment and its side effects for as long as possible. You may feel that the side effects of treatment might be worse than the effects of the cancer.

If the cancer starts changing or you get symptoms, your doctor will usually advise you start hormonal therapy to control the cancer. If you are older, you may never need treatment for the cancer at all.

#### Surgery

An operation 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 usually have radiotherapy afterwards.

Other types of surgery are sometimes done to relieve symptoms.

#### Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is sometimes used to treat locally advanced prostate cancer that is harder to treat. It is given with hormonal therapy. You usually have it before treatment with radiotherapy.

#### How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

#### Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

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

The MDT will usually include the following professionals:

- Urologist a doctor who treats problems with the prostate, kidneys, bladder and male reproductive system.
- Surgeon (urologist) a doctor who specialises in operating on the prostate.
- Oncologist a doctor who treats people who have cancer.
- Clinical nurse specialist (CNS) a nurse who gives information about cancer, and support during treatment.
- Radiologist a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include:

- a physiotherapist
- a dietitian
- a counsellor or psychologist.

#### Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see 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 treatment decisions.

Your specialist 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 most effective 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.

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 would cope with treatments if you have other health conditions
- whether the cancer is likely to cause you problems over your lifetime
- how you are likely to cope without having any treatment
- what treatment options you have if the cancer comes back.

## Treatment effects on your sex life

The effects of treatment on your sex life and relationships may be a big concern for you. Your doctor and nurse will explain the likely effects of treatments on your sex life.

Talking about your sex life with your healthcare team can be uncomfortable. But your doctor and nurse are used to talking about these issues, and it is important to ask questions. There are different treatments and support available to improve sexual difficulties. Your doctor and nurse can explain these. Try to let them know how you identify your gender or sexual orientation if there are issues you want to talk about. If you have a partner, it may help to bring them with you for support.

Prostate Cancer UK provides specific information and support for gay and bisexual men and trans women about the side effects of treatment and living with prostate cancer (see page 127).

# **Fertility**

Prostate cancer treatments can affect your fertility. If this is a concern for you, talk to your doctor or nurse. You may be able to store sperm before treatment starts. We have more information in our booklet Cancer and fertility - information for men (see page 122).

# 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 (verbal) 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.

## **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 specialist 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 specialist 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 (see page 122).

# Radiotherapy

Radiotherapy uses high-energy 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 control it for many years. Doctors call this radical radiotherapy. At the same time, they try to make sure radiotherapy causes as little harm as possible to healthy tissue and organs close by. These include the bladder, back passage (rectum) and bowel.

Radiotherapy for prostate cancer can be given in different ways:

- external beam radiotherapy radiotherapy is given from outside the body (externally) from a radiotherapy machine
- brachytherapy radiotherapy is given from inside the body (internally).

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 up to 6 months before radiotherapy. You usually continue to take hormonal therapy after radiotherapy. It may be given for up to 3 years.

# **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.

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

We have more information to help you give up smoking on our website (see page 122).

## What is external beam radiotherapy?

You have external beam radiotherapy as an outpatient in the radiotherapy department. Radiotherapy is given using a machine that is like a big x-ray machine. This is called a linear accelerator (often called a LINAC).

You usually have it as a series of short, daily treatments. The treatments are given from Monday to Friday, with a rest at the weekend. Radiotherapy is not painful, but you will need to lie still while you have it.

You usually have radiotherapy over 4 weeks. But in some hospitals, you may have it over 7 weeks. The total overall dose of radiation is higher when you have it over 7 weeks. When you have it over 4 weeks, the dose you get for each treatment session is higher. Both ways are effective, and the side effects are the same (see pages 45 to 50). You usually have radiotherapy over 4 weeks as it is shorter treatment.

Sometimes a type of radiotherapy called stereotactic ablative radiotherapy (or SABR) is given – see page opposite. You have this over a much shorter time because it involves much higher doses of radiation

Your doctor or nurse will explain more about this. 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, complex techniques that are used to treat prostate cancer more effectively. They can treat the cancer very exactly while protecting healthy tissue and reducing side effects.

# Intensity modulated radiotherapy (IMRT)

This is usually the type of radiotherapy you have. It uses advanced computers to calculate and deliver radiation directly to the cancer from different angles. IMRT shapes the radiation beams to the size of the tumour. The strength (intensity) of the dose can be changed depending on the tissue. Doctors can deliver an even higher radiation dose to the cancer while giving lower doses to healthy tissue.

# Volumetric modulated arc therapy (VMAT)

This is a newer technique that works in a similar way to IMRT. The radiation dose can be changed even more accurately during treatment. The machine rotates around you and quickly delivers radiotherapy beams in continuous arcs (curves) precisely to the cancer. VMAT can be given in shorter treatment sessions. It is currently only available in some hospitals. Doctors still need to find out if it is as effective as IMRT.

# Stereotactic ablative radiotherapy (SABR)

SABR allows large doses of radiotherapy to be given very precisely to small areas. SABR uses many smaller, thin beams of radiation. The beams are directed from different angles that meet at the tumour. It can deliver large doses of radiation to the prostate. This means you have all your treatment over a few days, instead of weeks.

SABR is not a standard treatment for prostate cancer, but it is currently being used in several hospitals. It does not seem to cause an increase in side effects.

We have more information on our website about SABR (see page 122).

## Planning external beam radiotherapy

Your cancer doctor plans your radiotherapy carefully to make sure it is as effective as possible.

During the planning visit, you will have a CT scan. The scan will help your doctor work out the exact dose and area of your treatment.

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. This is to get very clear CT pictures to help plan your treatment.

You may have a small amount of liquid passed into your rectum to empty your bowel. This is called an enema. The hospital will send you information if you need to prepare for your scan.

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

The person who gives you your treatment (radiographer) will 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 every treatment session. The marks 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 gold grains passed into your prostate using an ultrasound probe. These are called fiducial markers. They show the position of the prostate to help the radiographer see the position of the prostate before each session. This may help reduce side effects and any possible damage to organs close to the prostate. They are often used with SABR.



## Image-guided radiotherapy (IGRT)

To make sure the treatment is delivered very precisely, the radiographers take images before or during each session of radiotherapy. These show the size and shape of the cancer. and make sure the cancer is in the same position as in your planning scan.

## **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 reduces radiotherapy side effects of the rectum.

You need a general anaesthetic to have a rectal spacer put in. The doctor injects the spacer as a liquid through a small needle between the rectum and the prostate. It stays in place during radiotherapy and is gradually absorbed by the body. You may be a bit sore at the injection site for a short time. There is a risk of infection and you may need to take antibiotics to reduce this. There is a very small risk of complications if the spacer is not injected correctly, which may delay your treatment. Your doctor will explain what is involved and the possible risks and benefits.

Although the use of rectal spacers is approved by the National Institute for Health and Care Excellence (NICE), they are not available in all hospitals. You can talk to your doctor about this. They may be available through private healthcare.

## Treatment sessions

The radiographer will explain what will happen. At the start of each treatment session (called a fraction), 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 so you can have the radiotherapy. The treatment only takes a few minutes. You 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.

## 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 doctor, nurse, or radiographer 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. 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 (see page 122).

## Late effects

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 such as IMRT are reducing the risk of late effects, particularly on the bowel. Your doctor or nurse will explain these to you.

## Bowel side effects during treatment

Radiotherapy to the prostate can irritate the back passage (rectum) and bowel. You may get diarrhoea, wind and cramping pains in your tummy (abdomen). Your doctor can prescribe medicines to help control these side effects. Some men get pain in the back passage and may have some bleeding.

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 nurse or 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.

#### Late bowel effects

With modern radiotherapy techniques, late effects to the bowel are now 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 from the back passage, 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, ask to be referred to a bowel specialist (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 (see page 122).

## Bladder side effects during treatment

Radiotherapy can also cause inflammation of the bladder (cystitis). You may:

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

Your doctor 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.

Sometimes you may have difficulty passing urine and need to have a tube put into the bladder to drain urine (urinary catheter).

If you had urinary problems when you were diagnosed, you may find these improve after radiotherapy finishes.

#### Late bladder effects

The symptoms of bladder irritation you get with treatment (frequency and urgency) may not completely go away, or they may develop later.

The bladder lining may bleed easily, causing blood in your urine. 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 (see page 122).

## **Tiredness**

Radiotherapy causes tiredness, especially towards the end of treatment. It may last for a couple of months or longer after treatment has finished. Make sure you get plenty of rest. But try to balance this with regular physical activity, such as short walks. This will help give you more energy. We have more information about this in our booklets Coping with fatigue (tiredness) and Physical activity and cancer (see page 122).

**During the last week of my treatment,** the radiographer told me it was likely the side effects of the treatment could increase for a couple of weeks after the treatment finished. How right she was. **During the week following treatment** I have never felt so tired in all my life I was absolutely exhausted.

John, diagnosed with locally advanced prostate cancer

## Effects on the skin

The skin in the treated area may become red (if you have light skin) or darker (if you have dark skin). It may also become dry, flaky, and itchy. Sometimes the skin around the back passage (rectum) and scrotum becomes moist and sore. The radiographer or your specialist nurse will give you advice. They 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 after radiotherapy, but can develop slowly over 2 to 5 years. About 30 to 45 out of 100 men who do not have any problems before radiotherapy develop ED after treatment (30 to 45%).

You may have a higher risk of ED if:

- you are older older men are more likely to get ED than younger men
- you already had ED before treatment
- vou have other medical problems that also affect ED. such as diabetes or heart disease
- you are taking hormonal therapy drugs, which also affect ED and your desire to have sex.

Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help. After radiotherapy and brachytherapy, some men ejaculate little or no semen.

# 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 - information for men (see page 122).

## **PSA** levels after external radiotherapy

After radiotherapy, it can take time for your PSA level to drop. It usually goes down gradually. It may not get to its lowest level until about 18 months or longer after treatment. Your doctor and specialist nurse can give you more information about this. We have more information about PSA after treatment on our website (see page 122).

## **Brachytherapy**

Brachytherapy (internal radiotherapy) gives high doses of radiation directly to the prostate. Areas close by. such as the rectum and the bladder, get a much lower dose. 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 doctor or nurse will explain what will happen. They will usually give you written information.

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.

## HDR brachytherapy

You will have a general or a spinal anaesthetic (injection of painkillers into your spine) to have HDR brachytherapy. If you have a spinal anaesthetic, you will be awake but will not feel any pain. You may need to stay in hospital overnight.

### Having the tubes put in

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

Your doctor passes the tubes that deliver the brachytherapy into your prostate through the skin between the scrotum and back passage. They may also put a tube into the bladder to drain urine (catheter). This prevents any swelling of the prostate 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 doctor plan exactly how much radiation to give the prostate.

### **Having HDR**

The nurses take you to a treatment room that has the HDR machine. They attach the tubes 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 for. The treatment takes about an hour.

The tubes can be uncomfortable, and you must remain lying on your back 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 doctor or nurse 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 they explained.

You need to avoid doing heavy lifting or energetic physical activity for 2 to 3 days. The area between your legs can feel bruised and inflamed for a few days. Your doctor can prescribe painkillers to take.

## Side effects of brachytherapy

Brachytherapy causes similar side effects to external beam radiotherapy (see pages 45 to 50). 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.

## Effects on the bladder

If you already have difficulties passing urine (peeing), you will not usually have brachytherapy, as it may make bladder problems worse.

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

### You may also:

- have discomfort or pain passing urine and
- 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 takes 2 to 4 weeks.

Sometimes radiotherapy can narrow the urethra. This is called a stricture. This causes difficulties with passing urine. This may happen weeks, months or even years after treatment finishes. A stricture can be treated by passing a thin, plastic tube through the urethra to widen (dilate) it.

# **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 it reaching the prostate cancer cells.

Testosterone is important for:

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

## Hormonal therapy with radiotherapy

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

It may be given during radiotherapy, and before or after it. For example, you may have hormonal therapy:

- a few months before radiotherapy, to shrink the cancer and make treatment more effective (neo-adjuvant treatment)
- after radiotherapy, to reduce the chance of the cancer coming back (adjuvant treatment).

Your doctor will talk to you about how long you should take hormonal therapy for. They may advise you to have it for 2 to 3 years.

## Hormonal therapy on its own

If your doctors are using the watchful waiting approach (see page 62) 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 also causes side effects. It is important to talk to your doctor or nurse before you decide.

## Intermittent hormonal therapy

Intermittent hormonal therapy may sometimes be an option. This is where you stop taking the drugs and after a while start taking them again. It gives you a break from the side effects of hormonal therapy. It is not suitable for everyone and should only be done following your doctor's advice. Your 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 will advise you to start having hormonal therapy again.

## Types of hormonal therapy

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

## LHRH agonists

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

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<sup>®</sup>, Zoladex LA<sup>®</sup>)
- leuprorelin
- triptorelin (Decapeptyl<sup>®</sup> Gonapeptyl<sup>®</sup>).

A nurse or doctor at your GP practice or hospital can give you these drugs.

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 or into a muscle. You have these monthly, or every 3 or 6 months.

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 (Casodex®). You take it for a short time before and after starting the LHRH agonist.

## **Anti-androgen drugs**

These drugs stop testosterone from reaching the cancer cells. You take them as tablets. You may have anti-androgen drugs with radiotherapy, instead of having an LHRH agonist with radiotherapy. Or you may have an anti-androgen before and after the first injection of an LHRH agonist, to prevent any symptoms getting temporarily worse (tumour flare).

Anti-androgen drugs include:

- bicalutamide (Casodex<sup>®</sup>)
- cyproterone acetate (Cyprostat®)
- flutamide.

Cyporterone acetate and flutamide are less commonly used.

## 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 doctor or nurse will explain this to you. Some side effects are only likely to affect you when you have hormonal therapy for over 6 months.

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

## Common side effects

Common side effects include the following.

### Erection difficulties and reduced sex drive

Erection difficulties is called erectile dysfunction (ED) – see page 49. This usually improves after you stop treatment, depending on how long you take it for. But it may take a few months.

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.

#### Hot flushes and sweats

These may reduce as your body adjusts to hormonal treatment. They usually gradually improve after treatment finishes. Talk to your doctor 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. Regular physical activity can help reduce tiredness. Hot flushes may make sleeping difficult, so managing these may help you to sleep better. You may find our booklet Coping with fatigue (tiredness) helpful - see page 122.

### **Mood changes**

Talking to a family member, close friend or counsellor about how you feel may help with changes in your mood.

### **Memory and concentration problems**

These changes may be caused by the hormone 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 doctor or nurse will talk to you about this.

Other possible side effects include the following.

### Weight gain and loss of muscle strength

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

You can find more information in our booklets **Physical activity** and cancer and Healthy eating and cancer (see page 122).

## **Breast swelling or tenderness**

This is more common if you have flutamide or and bicalutamide over a longer period. Some men have low-dose radiotherapy to their 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.

### **Bone thinning (osteoporosis)**

The risk of this is increased with long-term hormonal treatment. You may have a scan to check your bones before you start treatment

Regular weight-bearing exercises such as walking, dancing, hiking, or gentle weight-lifting can help keep your bones healthy.

Your doctor may give you advice on diet and exercise. They may advise you to take calcium and vitamin D tablets. Depending on your bone health, they may talk to you about taking bone-strengthening drugs called bisphosphonates, or a drug called denosumab (Prolia®).

We have information you may find helpful in our booklet Bone health (see page 122).

### Increased risk of heart disease and diabetes

Not smoking, being physically active, eating healthily and keeping to a healthy weight can help reduce these risks. We have more information in our booklets Physical activity and cancer and Healthy eating and cancer (see page 122).

# Watchful waiting

Your doctor might talk to you about watchful waiting (watch and wait) if:

- you are older and do not have symptoms
- you have another medical condition that makes having treatment difficult.

Or you may choose this approach if 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 can have treatment if there are signs the cancer is growing, or if it is starting to cause symptoms.

Instead of having treatment you see your doctor regularly, usually your GP. They will ask if you have any new symptoms, such as difficulty passing urine (peeing) or bone pain. If you do have symptoms, you may have regular blood tests to check your PSA levels.

If you have 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 aim of the surgery is to remove all of the cancer cells.

This operation is not always suitable when the prostate cancer is locally advanced. It may not be possible to remove all the cancer cells that have spread outside the prostate. Your doctor can tell you whether a prostatectomy would be suitable for you or if other treatment, such as radiotherapy, may be best for you (see pages 38 to 53).

There are other types of surgery that can help with the symptoms of locally advanced prostate cancer. A transurethral resection of the prostate (TURP) does not treat the cancer, but it may help with symptoms such as difficulty passing urine (peeing) – see pages 74 to 76. It is sometimes done before other treatments such as radiotherapy.

Before the operation, the surgeon (a urologist) will explain what will happen and tell you about any possible side effects (see pages 71 to 76).

## Types of operation

There are different ways of doing a prostatectomy. Your surgeon will explain the type of operation you will have. It is often done using laparoscopic (keyhole) surgery, with or without a robotic assisted technique. But it is also sometimes done using open surgery.

During the operation, the surgeon usually removes the seminal vesicle which 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.

## Laparoscopic (keyhole) prostatectomy

In this operation, your surgeon does not need to make a large cut. Instead, they remove the prostate using 4 or 5 small cuts (each about 1cm long) in the tummy (abdomen).

The surgeon puts a small tube with a light and camera on the end (laparoscope) through one of the cuts. This shows an image of the prostate on a video screen. They use smaller, specially designed equipment to cut away the prostate from surrounding tissues. They remove the prostate through one of the small cuts.

# Robotic-assisted laparoscopic prostatectomy

This is when a laparoscopic prostatectomy is assisted by a machine. It is now a very common way of doing a laparoscopic prostatectomy. Instead of the surgeon holding the tube with the camera (laparoscope) and the surgical equipment, they are attached to robotic arms. The surgeon controls the robotic arms, which they move very precisely. This means the nerves that control erections and passing urine are less likely to be damaged. Your stay in hospital is also likely to be shorter if the robot is used.

Surgeons need special training to do this type of surgery. This means it is not available in all hospitals in the UK. Your surgeon will tell you if it is suitable for you and where you may be able to have it done.

## Open prostatectomy

The surgeon makes a cut in your lower tummy (abdomen), so they can remove the whole prostate. Or, sometimes they remove the prostate through a cut they make in the area between the scrotum and the back passage. This area is called the perineum.



## **Before surgery**

Before the operation, your surgeon or specialist nurse will explain the possible risks and side effects (see pages 71 to 76).

You usually have an appointment at a pre-assessment clinic to have tests to check your general health. The nurses may also advise you on what you can do to be fitter for surgery, such as giving up smoking or reducing your weight.

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.

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.

# After your prostatectomy

You will be encouraged to start moving around as soon as you can after your operation. This can help reduce the risk of complications such as blood clots. You may also need to have injections when you go home to prevent blood clots. The nurses can tell you more about this.

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

### Wound

If you have had an open prostatectomy, you will have a wound on your tummy or a wound between your scrotum and back passage. After a robotic or laparoscopic prostatectomy, you will have a few small wounds in the tummy area.

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 will advise you on how to take care of your wound. They will advise you what to look out for and who to contact if you have any concerns.

## **Pain**

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 staff on the ward if you are still in pain. You will be given a supply of tablets to take home with you.

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

## Catheter

You will have a tube (catheter) to drain urine from the bladder into a bag. Your catheter will usually stay in for a short time after you go home. The catheter lets urine drain while any swelling settles down and the urethra heals. The nurses will explain what to expect. Try to drink plenty of fluids to help keep the catheter draining well.

The nurses will show you how to look after your catheter before you go home. They will give you some spare bags. A district nurse can visit you at home if needed. If you have any problems with your catheter, contact your doctor, nurse, or the ward as soon as possible. The catheter is often removed at the clinic 1 to 2 weeks after the operation.

It is normal to leak urine for a period of time after the catheter has been removed. Your doctor and nurse will talk to you about this.

### Going home

If you had laparoscopic or robotic surgery, you can usually go home after 1 to 2 days. After open surgery, it is usually between 3 and 7 days.

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 doctor or nurse 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 on sex and prostate cancer on our website (see page 122).

### Follow-up after surgery

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

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

### Side effects of a radical prostatectomy

### **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 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 if:

- you had erection problems before treatment
- 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) – see pages 74 to 76
- 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 (see pages 54 to 61) or radiotherapy (see pages 38 to 53).

A prostatectomy can quickly cause erectile dysfunction (ED) problems. You may be offered penile rehabilitation using different ED treatments soon after treatment. This is called an ED recovery package. We have more information about treatments to help ED (see pages 97 to 99).

### **Ejaculation**

If 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 doctor or nurse if you are having this problem. They may be able to give you some advice.

### Infertility

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

It is important to talk to your cancer doctor or specialist nurse about fertility before treatment. It may be possible to store sperm before your surgery.

### Bladder problems

Urine leaking from the bladder (urinary incontinence) is a less common side effect of a prostatectomy. It is usual to have some incontinence when the catheter is first removed. This 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 can wear a pad to manage the incontinence.

Sometimes, you may have some incontinence when you cough, sneeze, or exercise. This is called stress incontinence. It is rare to be completely incontinent. If you are having problems, talk to your doctor or nurse. They can refer you to a continence team, who can give you advice about treatments. If these are not successful, you may be able to have an operation.

Another less common side effect of surgery is scarring to the entrance of the bladder (the bladder neck) or the urethra. 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 your operation, talk to your cancer doctor or specialist nurse.

### Macmillan toilet card

If you need to use a toilet urgently, you can show this card 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.

### Transurethral resection of the prostate (TURP)

Your doctor may offer you a transurethral resection of the prostate (TURP) if the cancer is blocking the urethra. This is the tube that drains urine from the bladder. The aim of the surgery is to remove the blockage, which can help with problems passing urine and improve your symptoms.

You may have a TURP before radiotherapy (see pages 38 to 53). Radiotherapy can make passing urine more difficult during and after treatment.

A TURP can be done under a general anaesthetic. Or, you may have a spinal anaesthetic (epidural). You have an injection of anaesthetic into your spine. This temporarily numbs the lower part of your body so you do not feel anything.

During surgery the surgeon passes a thin tube, which contains a cutting instrument and tiny camera, through the urethra into the prostate. They use the cutting instrument to shave off the inner area of the prostate and to unblock the urethra.

A TURP can also be done using a special laser. This is only done in some specialist treatment centres. Your doctor will advise you if this is suitable for you.

### After your TURP

You will be encouraged to start moving around as soon as you can after your operation. This can help reduce the risk of complications.

After a TURP, you will usually have a drip (intravenous infusion) into a vein in your arm. This will stay in for a few hours after your operation, until you are eating and drinking again. You can usually go home after 3 or 4 days.

### Catheter

You will have a tube (catheter) to drain urine from the bladder into a bag. 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 your bladder. The blood will slowly clear from your urine and then the catheter can be taken out.

You may find it difficult to pass urine without the catheter at first, but this will improve. You may have urinary incontinence after a TURP, but this usually improves within a few weeks.

You may still get the feeling that you want to pass urine. 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 doctor or nurse.

You may need to keep the catheter in 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 nurse will show you how to look after your catheter. They can also arrange for a district nurse to visit you at home. When the swelling goes down, the catheter can be removed.

### Pain

You may have pain and discomfort for a few days after your operation. You will be given painkillers to help with this. If they do not help, tell your doctor or nurse. They can give you another type of painkiller.

### 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 neck of your bladder. This is where the urethra joins on to the bladder. It means that during ejaculation, semen goes backwards into the bladder instead of through the urethra in the normal way. After an ejaculation, your urine may look cloudy. This is because there is semen in the bladder, but this is harmless.

### **Erection problems**

You may have problems getting an erection after the TURP. This is called erectile dysfunction (ED). It might depend on whether you had problems getting an erection before the operation. Your surgeon can tell you more about your risk of erection problems.

### Difficulties passing urine

Sometimes, TURP can cause some long-term difficulties with passing urine.

# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is occasionally used as one of the treatments for locally advanced prostate cancer. It is given in addition to hormonal treatment

Your doctor will explain if chemotherapy is a suitable treatment for you. This depends on the risk of the cancer coming back. Your doctor looks at the stage and grade of the cancer to work this out (see pages 19 to 23). It may be given if:

- the cancer is bigger
- the cancer has spread to the pelvic lymph nodes
- the PSA level and Gleason score are very high.

Chemotherapy may be given with hormonal therapy before starting radiotherapy treatment. Chemotherapy usually begins within 12 weeks of starting hormonal therapy. Radiotherapy will start when you have recovered from your chemotherapy and when the PSA in your blood has fallen to a very low level.

You need to be well enough to cope with the side effects of chemotherapy. It may be more suitable if you are younger and have no other health problems.

You and your doctor can talk about the possible benefits and disadvantages before you make a decision.

### Having chemotherapy

The chemotherapy is given into a vein (intravenously). The drug gets into the blood and can reach cancer cells all over the body.

The drug that is used is called docetaxel (Taxotere®). You usually have docetaxel every 3 weeks for 6 sessions.

### Side effects

Your doctor or nurse will explain the most common and serious side effects of docetaxel (Taxotere®). They will tell you how they can be treated or managed. Always tell them about your side effects. The doctor, nurse or pharmacist can prescribe drugs to help control them.

They will talk to you about your risk of getting an infection and signs to look out for. Infection can be a very serious problem. Call the hospital's 24-hour helpline straight away if you have signs of infection or feel unwell. Always contact them about any side effect you are worried about or making you feel unwell.

Most side effects stop or slowly go away when chemotherapy finishes.

We have more information in our booklets **Understanding** chemotherapy and Side effects of cancer treatment (see page 122).



## Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer.

Trials can also look at improving things like diagnosis and symptom management.

### Taking part in a 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. Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials on our website (see page 122).

The cancer had spread to a lymph node and a seminal vesicle. Because of this, I was put in for a clinical trial for 2 years before we could attempt radiotherapy.

Paul, diagnosed with locally advanced prostate cancer

### Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

# AFTER TREATMENT

Follow-up after treatment	86
Well-being and recovery	88
Sex	91
Relationships	100



# Follow-up after treatment

After treatment has finished, you will have follow-up appointments. Your doctor or nurse will talk to you about the type of follow-up you will have.

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 will usually ask questions about the side effects of treatment and if you have any bowel, bladder or sexual problems.

### 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:

- at least every 6 months for the first 2 years
- at least once a year after the first 2 years.

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

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 one rise in the PSA level to find if prostate cancer has come back. Doctors also look at how quickly it rises.

### **Symptoms**

It can also be helpful to be aware of symptoms to look out for. Symptoms may be linked to long-term or late side effects of treatment. Do not wait until your appointment to report any new symptoms or symptoms that do not go away. Tell your team about them immediately. For example, these symptoms may include:

- urinary or bowel symptoms (including bleeding from the bladder or back passage)
- pain in any area of the bones
- any changes in feeling or 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, friends or a support organisation. You can also call the Macmillan Support Line on **0808 808 00 00**, 7 days a week, 8am to 8pm.

### 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

# Well-being and recovery

Even if you already have a healthy lifestyle, you may choose to make some positive lifestyle changes after treatment. Making small changes can improve your health and well-being. 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 well and keep to a healthy weight

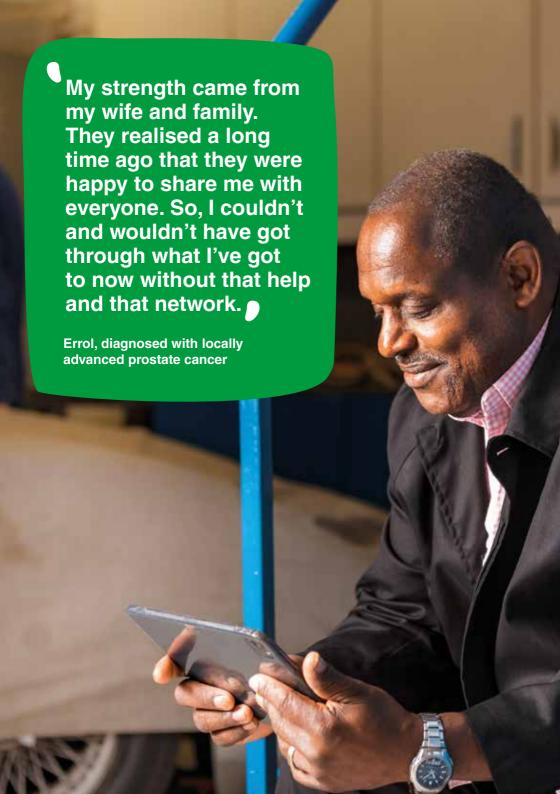
Your GP can advise you and give you information about your ideal weight. Eating a healthy diet and keeping to a healthy weight reduces the risk of heart problems, diabetes and developing some other cancers. Try to:

- 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.

We have more information in our booklets **Physical activity** and cancer. Bone health, Heart health and cancer treatment, and Healthy eating and cancer (see page 122).



### Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases your risk of bone thinning (osteoporosis) and is a major risk factor for smoking-related cancers and heart disease. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live (see page 131).

### Look after your bones

Hormonal treatments 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. If you smoke, you should stop as this can also increase your risk of bone thinning.

### Limit alcohol

Drinking guidelines recommend that you should not regularly drink more than 14 units of alcohol in a week. Try to also have a few alcohol-free days each week.

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

There is more information about alcohol and drinking guidelines at drinkaware.co.uk

### Sex

Treatments for prostate cancer can cause sexual difficulties. Or you may have side effects that make you feel less interested in having sex. These can include:

- tiredness
- changes to your bladder or bowel
- hormonal effects, such as weight gain or breast swelling.

We have included information about managing the side effects of treatment within this booklet. As your side effects improve, you may feel more interested in having sex.

If cancer and its treatments affect your sex life, 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 doctor or nurse for advice.

Certain lifestyle changes may help improve body image concerns, such as being more physically active, eating healthily and managing your weight. Ask your doctor or nurse for advice.

We have more information in our booklets Body image and cancer, Physical activity and cancer and Managing weight gain after cancer treatment (see page 122).

### Sexual difficulties

Prostate cancer treatments can have a direct effect on your sex life. For example, they can cause difficulties getting or keeping an erection. This is called erectile dysfunction (ED) - see page 49.

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

Cancer treatments may cause difficulties getting or keeping an erection. After a prostatectomy this may happen soon after treatment. With radiotherapy, you may not have ED problems immediately after treatment, but it may develop over years.

Treatment can also affect your ability to have an orgasm or to ejaculate. After prostatectomy you will not ejaculate but can still have an orgasm. After external radiotherapy or brachytherapy, you do not usually produce much semen but can still orgasm. Read about radiotherapy on pages 38 to 53.

Some treatments can reduce your sex drive (libido). Hormonal therapy, which you may have with radiotherapy, lowers your desire to have sex (libido). It may also lower your ability to get and maintain an erection. Read about hormonal therapy on pages 54 to 61.

If you are having sexual difficulties, there are different ED treatments to help you (see pages 97 to 99).

### Talking about sex

You may find it difficult to talk about sex with your doctor or nurse. But it is important to have your questions answered and to get the help you need. Your doctor, specialist nurse or GP should make you feel comfortable during conversations about sex.

You may want to think about whether 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 doctor or nurse can refer you to an ED clinic or a sex therapist.

If you find it difficult talking to your doctor or nurse or getting information, there is other support available. You can talk to in confidence to a cancer information nurse specialist on our Macmillan Support Line or through email (see page 124). Prostate Cancer UK also has a helpline where you can talk or chat online to a specialist prostate nurse (see page 127).

### Sex and treatment

If you have questions about sex during or after treatment, ask your doctor or 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 may not feel up to it. You may decide to wait until your side effects improve.

We have more information in our **Understanding pelvic** radiotherapy (see page 122).

### If you identify as LGBT+

There may be times when it helps your healthcare team to know how you identify your gender or sexual orientation. It may help you feel better supported. They 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 well-being.

### Prostate treatment and anal sex

Pelvic radiotherapy can affect the back passage (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 doctor or 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 prostatectomy, you are usually advised to wait for 6 weeks before you receive anal sex.

Prostate Cancer UK has more information for gay and bisexual men and trans (transgender) women (see page 127).

If your healthcare team cannot help, they can refer you to a sex therapist or another specialist who can. If you want to talk things through, call the LGBT Foundation for confidential advice and support (see page 134).

I have probably less than 20% feeling below my belly button. Erectile function is probably non-existent. But what I've learned through my journey with this is that some people will get a lot more than that. And it's how you manage what you have.

Errol, diagnosed with locally advanced prostate cancer

### Managing sexual difficulties

There are practical ways to help manage sexual difficulties. Your doctor or nurse will give you information about these.

If you are taking 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.

Most treatments aim to increase the blood supply to the penis. You may need to try a treatment a few times to start with. Some men may use more than one method.

Because a prostatectomy can cause ED problems quickly, you may be offered penile rehabilitation soon after treatment. This is called an ED recovery package. You regularly use one or more treatments, such as tablets or a pump, to encourage blood flow to the penis. This is to help the penis recover - it is not just for sex. When you are ready to start having sex, you should have a better chance of getting an erection. Your doctor or nurse can tell you more about this.

### **Tablets**

This is the most common treatment for ED. These tablets work by improving the blood supply to the penis. You take them before you have sex. There are different ones you can try. Some may work better for you than others. You need to have sexual stimulation to get an erection. If you have heart problems, these may not be recommended for you. They should not be taken with certain drugs. Your doctor or nurse can explain more about this and their possible side effects.

### Tablets to treat ED include:

- sildenafil (Viagra®) you take it about 60 minutes before sex and it should be prescribed by your GP
- vardenafil (Levitra®) this is like sildenafil and you take it 25 to 60 minutes before sex
- avanafil (Spedra®) you take it 15 to 30 minutes before sex
- tadalafil (Cialis®) you take it at least 30 minutes before sex.

### Other treatments for ED

If drug treatment does not work for you or is not suitable, talk to your doctor about other possible options.

### **Injections**

These may work better than tablets if you have ED that is caused by nerve damage. You inject a drug called alprostadil directly into the penis, using a small needle. The drug improves blood flow in the penis. This causes an erection in 5 to 20 minutes. A healthcare professional will give you the first dose and show you how to do the injection yourself. You start with a low dose of the injection, which you can increase to find the right dose for you.

### Pellets or creams

You can get alprostadil as pellets (MUSE®) or as cream (Vitaros®). You put it in the opening of the penis to cause an erection. The drug may cause a burning feeling in the urethra or pain in the penis as it starts working. A healthcare professional will explain more about it and its side effects. They will show you how to do it and give you the first dose.

### **Pumps**

Vacuum pumps can be used to produce an erection. They are also called vacuum erection devices (VEDs). The pump is a hollow tube that you put your penis into. It makes the penis fill with blood by creating a vacuum. You put a stretchy ring around the base of the penis to hold the erection. You should not wear it for more than 30 minutes.

### **Penile implants**

These are sometimes used after other methods have been tried. You need a small operation to insert the implant into your penis. One type uses semi-rigid rods that keep the penis fairly stiff all the time. They allow the penis to be bent down when an erection is not needed. The other type uses inflatable rods that can be turned on when needed to produce an erection.

### Infertility

Most treatments for prostate cancer are likely to cause infertility. This means you will no longer be able to get someone pregnant. If you want to have children, this can be very upsetting.

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

We have more information in our booklet Cancer and fertility - information for men (see page 122).

# Relationships

### If you have a partner

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. You may also find new ways to share sexual pleasure.

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 single

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 (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support (see page 128).



You have to improvise the best way possible, but you can't let it beat you.

Errol, diagnosed with locally advanced prostate cancer



# YOUR FEELINGS AND RELATIONSHIPS

Your feelings	104
Coping with your emotions	108
If you are a family member or friend	109
Talking to children about cancer	110

# Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

### Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

### Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

### Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

### **Avoidance**

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

# **Anger**

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

#### **Guilt and blame**

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit macmillan.org.uk/supportgroups You can also talk to other people affected by cancer on our Online Community. Visit macmillan.org.uk/community

## If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

You may find our booklet How are you feeling? The emotional effects of cancer helpful (see page 122).

# Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

# 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 might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet Talking with someone who has cancer (see page 122).

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 Looking after someone with cancer (see page 122).

# Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

### **Teenagers**

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children** and teenagers when an adult has cancer (see page 122).

# FINANCIAL SUPPORT AND WORK

Financial help and benefits	114	
Work	118	



# Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

## Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

#### **Benefits**

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to gov.uk if you live in England, Wales or Scotland, or nidirect.gov.uk if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

# **Employment and Support** Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

#### Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

### **Personal Independence Payment**

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

#### Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

# Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with guickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

# **Help for carers**

Carer's Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

### **Macmillan Grants**

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

#### Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on 0808 808 00 00.

We have more information in our booklet Travel and cancer (see page 122). Our Online Community forum on Travel insurance may also be helpful.

### More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on 0808 808 00 00.

You can also get information about benefits and other types of financial help from Citizens Advice or Advice NI if you live in Northern Ireland (see page 133).

Our booklet **Help with the cost of cancer** has lots more information (see page 122).

# 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 soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

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

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful (see page 122). There is also lots more information at macmillan.org.uk/work

## **Employment rights**

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet Your rights at work when you are affected by cancer has more information (see page 122).



# FURTHER INFORMATION

About our information	122
Other ways we can help you	124
Your notes and questions	136

# About our information

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

### Order what you need

You may want to order more booklets or leaflets like this one. Visit be.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

- eBooks
- 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 cancerinformationteam@ 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 try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

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. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at 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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on 0808 808 00 00 or email us via our website, macmillan.org.uk/talktous

#### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

#### 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 to bring people together in their communities and online.

#### Support groups

Whether you are someone living with cancer or a carer, 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

#### The Macmillan healthcare team

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.

## 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.

#### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

#### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

#### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on 0808 808 00 00 to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/financialsupport to find out more about how we can help you with your finances.

### Help with work and cancer

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

#### **Work support**

Our dedicated team of work support advisers can help you understand your rights at work. Call us on 0808 808 00 00 to speak to a work support adviser (Monday to Friday, 8am to 6pm).

# 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 Email help@bladderandbowel.org www.bladderandbowel.org

Provides information and advice on a range of symptoms and conditions related to the bladder and bowel, including incontinence, constipation and diverticular disease.

#### **Orchid**

Helpline 0808 802 0010 Email info@orchid-cancer.org.uk www.orchid-cancer.org.uk

Funds research into men's cancers and their diagnosis. prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid Male Cancer Information Nurses.

#### **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

Email info@prostatescotland.org.uk

#### www.prostatescotland.org.uk

A Scottish charity set up to provide information, advice and support on prostate health and diseases of the prostate. You can watch videos online and download free leaflets and booklets

#### **Tackle Prostate Cancer**

Tel 0800 035 5302

Email info@tackleprostate.org

www.tackleprostate.org

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

#### Support with sexual issues

#### College of Sexual and Relationship Therapists (COSRT)

Tel 020 8106 9635

www.cosrt.org.uk

The UK's leading membership organisation for therapists specialising in sexual and relationship issues.

#### **Prostate Cancer UK sexual support service**

Specialist nurses 0800 074 8383

www.prostatecanceruk.org/get-support/sexual-support

A service to for you or your partner to talk to a specialist nurse with an interest in helping with sexual problems after treatment for prostate cancer.

#### **Sexual Advice Association**

#### www.sexualadviceassociation.co.uk

Aims to improve the sexual health and well-being of men and women, and to raise awareness of how sexual conditions affect the general population

#### General cancer support organisations

#### **Cancer Black Care**

Tel 020 8961 4151

#### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

#### Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)

Email nurseline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland

#### **Cancer Research UK**

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)

#### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Cancer Support Scotland**

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)

Email info@cancersupportscotland.org

#### www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### **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

Email enquiries@maggies.org

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 3000 118** (Mon to Fri, 10am to 2pm)

Email helpline@pennybrohn.org.uk

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

#### Riprap

#### www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

#### **Tenovus**

Helpline 0808 808 1010

(Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)

#### 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

#### Health and Social Care in Northern Ireland

#### online.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 Direct Wales**

#### www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

#### **NHS Inform**

Helpline **0800 22 44 88** (7 days a week 8am to 8pm)

#### 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- and illness-related websites.

#### Counselling

#### **British Association for Counselling** and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)

Email bacp@bacp.co.uk

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 their 'How to find a therapist' page.

#### **UK Council for Psychotherapy (UKCP)**

Tel 020 7014 9955

Email info@ukcp.org.uk

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** (Mon to Fri, 9am to 6pm) Email info@mind.org.uk

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

Email advice@advice.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

#### **Benefit Enquiry Line Northern Ireland**

Helpline **0800 232 1271** 

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm) Textphone 028 9031 1092

#### www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you are eligible for.

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their 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** (Daily, 8am to 7pm)

#### 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.

#### **LGBT-specific support**

#### **LGBT Foundation**

Tel **0345 330 3030** (Mon to Fri, 9am to 0pm)

Email helpline@lgbt.foundation

#### www.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.

#### **Live Through This**

#### www.livethroughthis.co.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 produce resources about LGBT cancer experiences. LTT run a peer support group with Maggie's Barts.

#### **Cancer registries**

#### The cancer registry

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 one in each country in the UK:

#### **National Cancer Registration and Analysis Service**

Tel 0207 654 8000 Email enquiries@phe.gov.uk www.ndrs.nhs.uk Tel (Ireland) 0214 318 014 www.ncri.ie (Ireland)

#### **Scottish Cancer Registry**

www.ndrs.nhs.uk/cancer-registration-your-rights-andprivacy

#### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

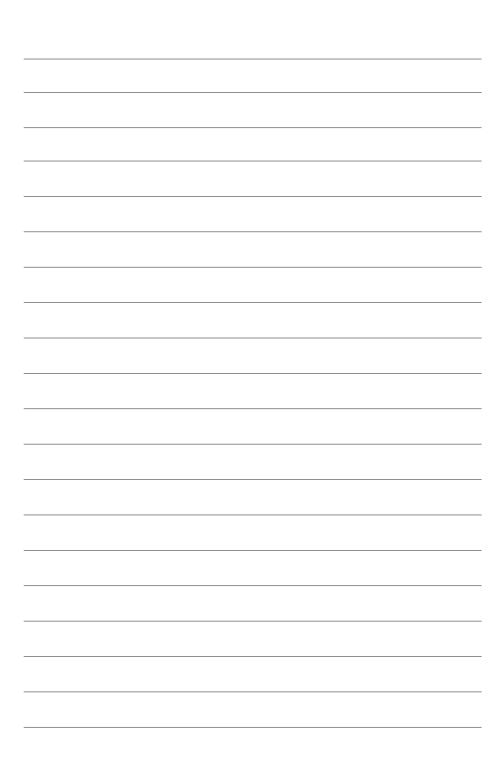
Tel 0292 010 4278

phw.nhs.wales/services-and-teams/welsh-cancerintelligence-and-surveillance-unit-wcisu

#### **Northern Ireland Cancer Registry**

Tel 0289 097 6028 Email nicr@qub.ac.uk www.qub.ac.uk/nicr

# 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 Jim Barber, Consultant Clinical Oncologist, and Dr Ursula McGovern, Consultant Medical Oncologist.

With thanks to: Jane Booker, Macmillan Urology Clinical Nurse Specialist; Mr Christian Brown, Consultant Urological Surgeon; Sharon Clovis, Prostate Clinical Nurse Specialist; Mr Daniel Good, Consultant Urological Surgeon; Dr Mohammed Kagzi, Consultant Clinical Oncologist; Dr Duncan McLaren, Consultant Clinical Oncologist; David Stafford, Macmillan Lead Nurse in Urology Cancer Services; and Professor Jonathan Waxman, Professor of Oncology.

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 cancerinformationteam@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 cancerinformationteam@macmillan.org.uk

C. Parker, E. Castro, K. Fizazi, et al. Prostate cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2020, Volume 31, Issue 9, p1119-1134. Available from www.esmo.org/guidelines/ genitourinary-cancers/prostate-cancer

National Institute for Health and Care Excellence (2019) Prostate cancer: diagnosis and management (NICE guideline NG131) Available from www.nice.org.uk/guidance/ng131

# 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, benefits 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

#### Share your cancer experience

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

#### 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.

#### 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?

#### Raise money

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

#### **Give money**

Big or small, every penny helps.

To make a one-off donation see over.

# Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

Please fill in your personal details	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.	
Mr/Mrs/Miss/Other		
Name		
Surname		
Address	☐ I am a UK tax payer and I would	
Postcode	like Macmillan Cancer Support to treat all donations I make or have	
Phone	made to Macmillan Cancer Support in the last 4 years as Gift Aid	
Email	donations, until I notify you otherwise.	
Please accept my gift of £ (Please delete as appropriate)	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.	
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my:	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.	
Visa / MasterCard / CAF Charity Card / Switch / Maestro	In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.	
Card number  Valid from Expiry date	If you would rather donate online go to macmillan.org.uk/donate	
Issue no Security number	Registered with FUNDRAISING	
	REGULATOR	
Signature		
Date / /		

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ